

PHYSICAL EDUCATION FOR STUDENTS WITH SPINA BIFIDA:
MOTHERS' PERSPECTIVES

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ABSTRACT

The purpose of this study was to gain an understanding of mothers' perspectives of their children's experiences in inclusive physical education. It describes the value mothers placed on physical education, the meaning they ascribed to their children's physical education experiences, the role of the Personal Program Plan (PPP) in mother's communication with the school, and the other means of communication they used to share their thoughts about children's participation. The stories of mothers of elementary (1 boy, 3 girls) and secondary (2 boys, 1 girl) aged children with spina bifida were collected and analyzed using the hermeneutic phenomenological methods of semi-structured interviews, artifacts, documents, and field notes. The thematic analysis revealed three themes: A Good Thing But..., Connection to Disability Sports, and Beyond the Curriculum. Peters' (1996) model of disablement provided the conceptual framework for the interpretation of the findings.

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1. INTRODUCTION

Former professional experience as a *disability sports coach in swimming and the coordinator of disability sports* caused me to reflect upon parents' roles in their children's physical education programs. While I was providing several physical activity programs to children with disabilities, I developed close relationships with the parents. They often discussed their children's physical education programs before and after my physical activity programs. I tried as best I could to provide the parents with information that would be relevant to their children's physical education programs. Although the parents were enthusiastic about their children's involvement in my programs, they appeared to be less interested in influencing their children's physical education programs at school. This discrepancy intrigued me and as a result the parents' perspectives of their children's experiences in physical education became the focus of my study.

Parents have been identified as fundamental partners in the organization and development of educational programs for children with disabilities (Lytle & Bordin, 2001; Manitoba Minister of Education Training and Youth, 1998; 2001). Their involvement has primarily been during the personal program plan (PPP) process. The PPP is a written statement created and developed as "parents, educators, and the student work together to confirm that the student is able to achieve his or her designed goals"

(Auxter, Pyfer, & Huettig, 2001). The PPP process has been widely implemented across North America (Block, 2000; Sherrill, 1998). Parents' input into their children's educational outcomes is imperative because the parents and their children will be most impacted by the success or failure of the educational process.

The merger of special education with regular education during the 1980s resulted from a shift away from a *services based* educational paradigm towards a *supports based* paradigm (Polloway, Smith, Patton, & Smith, 1996). A *services based* education paradigm was founded on the assumption that if students received specialized educational services (e.g., skill upgrading within a self-contained setting), provided by specifically trained teachers, they would, in time, be integrated back into the regular educational stream and ultimately the larger community. Special education classrooms, taught by special education teachers, were part of the services based educational landscape. A drawback that emerged from this paradigm was that many of the students never "earned their way out of the programs" and thus remained in special classes throughout their school years (Stainback & Stainback, 1990).

Parents and other advocates challenged the dual system of education (i.e., general education and special education) due to its fiscal inefficiencies and unfulfilled promises. The *supports-based* paradigm emerged. Proponents of this paradigm assumed that with proper and adequate support, individuals with disabilities would achieve success by remaining in the mainstream environment and participate fully in family, school and community activities (Polloway et al., 1996). What Polloway et al. (1996) referred to as a supports-based paradigm has been given the label of *inclusion* within the context of educational programming (Winzer, 1996). Stainback & Stainback (1990)

stated that an inclusive school was “a place where everyone belongs, is accepted, supports, and is supported by his or her peers and other members of the school community in the course of having his or her educational needs met” (p. 3). McGregor & Vogelsberg (1998) further defined inclusion as:

... the provision of services to students with disabilities, including those with severe impairments, in the neighbourhood school, in age-appropriate general education classes, with the necessary support services and supplementary aids (for the child and the teacher) both to assure the child’s success – academic, behavioural and social – and to prepare the child to participate as a full and contributing member of the society. (p. 9)

The ‘inclusion’ ideology enabled many students with disabilities to achieve both social and academic success in general education environments that reflect the heterogeneous make up of society (Block, 2000; Cheney, 2000).

Prior to the full merger of general and special education, physical education was one of the first subject areas students with disabilities attended within the general educational setting (Sherrill, 1998). General physical education continues to be the preferred program setting for students with disabilities (Cheney, 2000; Stainback & Stainback, 1990; Yun, Shapiro, & Kennedy, 2000). Nevertheless, successful participation in the general program requires that adaptations be made to the learning environment. For example, students who are Deaf may need the support of interpreters and students with emotional disorders may require instructional assistants (Houston-Wilson & Lieberman, 1999).

The process of inclusive physical education has been of considerable interest to adapted physical activity researchers. In coming to better understand the process and identify best practices, the perspectives of teachers (Kowalski & Rizzo, 1996; LaMaster, Gall, Kinchin, & Siedentop, 1998; Lieberman, Houston-Wilson, & Kozub, 2002; Rizzo & Vispoel, 1991; Verderber, Rizzo, & Sherrill, 2003; Vogler, Koranda, & Romance, 2000), classmates without disabilities (Block & Zeman, 1996; Obrušníková, Válková, & Block, 2003; Verderber et al., 2003), and students with disabilities (Blinde & McCallister, 1998; Goodwin, 2001; Goodwin & Watkinson, 2000; Hutzler, Fliess, Chacham, & Van den Auweele, 2002; Suomi, Collier, & Brown, 2003) have been investigated. Absent from the discourse on inclusive physical education has been the perspective of parents.

The proposed study may deepen our understanding of parents' perspectives of their children's inclusive physical education experiences. The role parents play in sharing expectations, communicating concerns, and celebrating successes will also be explored.

2. REVIEW OF LITERATURE

2.1 Parents' Views of Inclusion

The efficacy of inclusion as an educational service has been studied from the perspectives of special and general education teachers, administrators, and students (Bain & Dolbel, 1991; Bennett, Deluca, & Bruns, 1997; Doubt & McColl, 2003; Giangreco, Dennis, Cloninger, Edelman, & Schattman, 1993; Wilson, 1999). Only recently, however, has attention been given to the role of parents of children with disabilities in the inclusive process. Increasingly, parents' attitudes toward inclusion (Bennett et al., 1997; Giangreco, Edelman, Cloninger, & Dennis, 1993; Hamre-Nietupski, Nietupski, & Strathe, 1992; Kasari, Freeman, Bauminger, & Alkin, 1999; Modell & Imwold, 1998), their evaluation of the effectiveness of inclusive placements (Erwin & Soodak, 1995; Ryndak, Downing, Jacqueline, & Morrison, 1995), and their involvement in the inclusive education process have been sought (Bennett et al., 1997; Soodak & Erwin, 2000).

Erwin and Soodak (1995) studied parents' experiences pursuing inclusive education placements for their children with disabilities. Parents were asked to discuss (a) how their child's educational placement came about, (b) how they defined inclusion, (c) their experiences of pursuing inclusive education, and (d) how the process of

pursuing inclusion affected them. In-depth semi-structured interviews were conducted with 9 mothers of children with moderate and severe disabilities, ranging in age from 5 to 19 years. The meaningfulness of inclusion to the parents was expressed in three themes (a) a sense of belonging, (b) equal access and opportunity, and (c) being part of group. The themes were reflective of the parent's perceptions that inclusion was a fundamental right of their children. Parents developed and used several strategies to secure an inclusive placement for their children. For example, parents became involved in the decision making process, sought the support of administrators, moved schools, secured advocacy support (e.g., other parents), and as a last resort turned to the courts and media. The findings of this study indicated that a strong partnership between the family and school is needed to ensure successful inclusive education experiences.

A further study conducted by Soodak and Erwin (2000) explored the experiences of parents of young children with disabilities (e.g., Down syndrome, autism, neurological impairment, and multiple disabilities) in inclusive education settings. Ten parents of children, aged 4-8 years were interviewed. Five themes emerged from the analysis of the interviews (a) the underlying values about inclusive education, (b) school climate, (c) personal perspectives, (d) roles and responsibilities, and (e) parent-professional partnerships. The study indicated that the climate of the school was an important factor in the degree to which parents were perceived as partners in the education of their children. Parent and professional partnerships were facilitated by trust, shared visions about children and schooling, shared commitment, and open communication. This study supported the role of parents as important and necessary to the success of inclusive education.

Ryndak et al. (1995) studied the impact of inclusive education settings as perceived by parents of children and youth with moderate and severe disabilities. They examined thirteen parents' perceptions of (a) skills acquired by their children who often receive educational services in inclusive settings, (b) the most significant benefit of inclusive services for their children, and (c) their vision for their child's future following inclusive educational services. The benefits perceived by parents were increased acquisition of academic, communication, and social skills and more appropriate behaviour and positive attitudes. The parents pointed out the development of social skills and behaviours as the most significant benefit of the inclusive education setting. Their perceptions of inclusive schooling were extremely positive.

Parents believe inclusive settings can improve social interaction and communication skills (Block, 1994; Giangreco, Dennis et al. 1993; Kasari et al., 1999; Ryndak et al., 1995). The importance of social skill development as an educational program outcome was emphasized by the parents (Hamre-Nietupski et al., 1992; Kolb & Hanley-Maxwell, 2003). In the study of Giangreco, Dennis et al. (1993b), the benefits of inclusion identified by parents were increasing personal enjoyment and friendship, appreciating individual differences among people, enhancing social/ emotional growth, and broadening their children's personal experiences.

Few studies have investigated parents' perceptions of inclusion specific to physical education. In one such study, Downing & Rebollo (1999) investigated the factors parents deemed essential for the placement of their children with disabilities into integrated physical education programs. One hundred parents of children with physical disabilities in mainstreamed classes from 6 elementary schools completed a 21 question

survey. Parents perceived the most important factors to be (a) class size and motivation for successful implementation of an integrated physical education program, (b) teacher, parent and administrative support and interest, and (c) physical health. In addition, parents suggested that cognitive skills, which are often used as primary placement determinants in special education classes, were less important for physical education placement. The findings of this study seem to suggest that parents are well informed about determinants for success in inclusive physical education and should therefore be included in the educational decision making process of their children.

2.2 Inclusive Physical Education

Inclusive physical education benefits many students (Block, 1999; 2000). According to professional opinion, students with disabilities have an opportunity to learn social skills in a more natural environment, to make new friendships with peers without disabilities, and to improve self-esteem (Suomi et al., 2003). Students without disabilities can learn about disabilities and come to a better understanding of individual differences (Block, 1994). Inclusive physical education is a process whereby all students share their differences and learn to respect each other's limitation and unique abilities (DePauw & Doll-Tepper, 2000). Block (2000) states social objectives, including appropriate cooperation and tolerance for varying abilities, can be enhanced through physical education. Goodwin (2000) described inclusive physical education as a learning environment that provides:

...all students with disabilities the opportunity to participate in regular physical education with their peers, with supplementary aides and support services as needed to take full advantage of the goals of motor skill acquisition, fitness, knowledge of movement, and psycho social well being, toward the preparation of students for an active lifestyle appropriate to their abilities and interests. (p. 15)

2.2.1 Goals of Physical Education

Physical education programs provide a planned sequence of activities to improve students' motor and cognitive skills, physical and motor fitness, and feelings of self-worth (Block, 2000; Gallahue, 1996; Kirchner & Fishburne, 1995). The affective, psychomotor, and cognitive domains frame the goals of physical education. Affective domain goals are designed to strengthen self-concept and body image, to reduce social isolation, develop social behaviours, and to improve attitudes toward physical activity. Psychomotor domain goals include learning fundamental motor skills and patterns and their application to physical activity environments, developing physical fitness, and becoming acquainted with community resources for recreation. Finally, the cognitive domain goals focus on the learning of play and game behaviour, enhanced perceptual motor function and sensory integration, and increased creativity in movement and thought (Grineski, 1993; Sherrill, 1998). The goals of physical education are (a) to develop positive attitudes toward physical activity, (b) to promote life-styles oriented to overall well being, and (c) to develop concept-based skills. Ultimately, the overall aim of physical education is to promote the physical well being and health of all students (Saskatchewan Education, 1999).

Knowledge of the goals and objectives of the physical education program is necessary for maximizing student learning, as well as for the writing of formal Personal Program Plans (PPP) for students with disabilities (Davis, 1989; Sherrill, 1998). Goals guide a person's activity and allow the instructor to measure performance (Bar-Eli, Hartman, & Levy-Kolker, 1994). Grineski (1993) states goal-directed programs motivate children to become physically fit, skillful, and knowledgeable. Goal utilization in instructional planning directs decision making about assessment and helps professionals and what instruments to administer to describe present level of performance in the PPP (Davis, 1989; Sherrill, 1998). Davis (1989) suggested the establishment of individualized goals in physical education, specific to students with disabilities, is essential for effective teaching and learning in physical education. Identifying goals and objectives is also important for the individualization of instruction.

2.3 Personal Program Plan (PPP) Process

A Personal Program Plan¹ (PPP) is a summary of the student's specific performance outcomes and related educational services provided during a school year (see Appendix A). It is a plan for instruction that guides teachers as they support

¹ The terminology varies by province in Canada. For example, the Ministry of Education in the province of British Columbia and Manitoba uses the 'Individual Education Planning (IEP)', the provinces of Ontario, Northwest Territories, Prince Edward Island, Quebec, Yukon use the 'Individual Education plans', the province of Alberta, Nova Scotia, and Newfoundland use the 'Individual Program Plan (IPP)', the province of Saskatchewan uses the 'Personal Program Plan (PPP)', and the province of New Brunswick uses the 'Special Education Plan'(SEP) (Alberta Education, 1996; British Columbia Ministry of Education, 2000; Manitoba Minister of Education Training and Youth, 1998; New Brunswick Department of Education, 1988; Northwest Territories Department of Education Culture and Employment, 2002; Ontario Ministry of Education, 2000; Saskatchewan Education, 1988)

students attain the skills and knowledge appropriate to their educational placement and meet the individual learning needs of the student (Manitoba Minister of Education Training and Youth, 1998, 2001; Ontario Ministry of Education, 2000; Saskatchewan Education, 2001). The National Education Steering Committee of the Moving to Inclusion initiative (1994) defined a PPP as:

...a written outline describing the learning expectations, indicators and strategies required to support a student's learning. It is an important part of the preparation and implementation of an educational program that focuses upon the strengths, needs, and interests of the students with a disability. (p.12)

The PPP is also a process that results in a written document designed for individual students with disabilities (Auxter et al., 2001; Sherrill, 1998). The intent of the PPP is to ensure that educational programs address the individual, educational, and developmental needs of the student relative to the student's disability (Edmiaston, Dolezal, Doolittle, Erickson, & Merritt, 2000). It delineates the supports needed for students to successfully achieve the goals and objectives outlined for each area of study. The role of parents in the development of the PPP has been open to numerous interpretations (Garriott, Wandry, & Snyder, 2000).

2.3.1 Purpose and Function

The PPP acts as a planning document, a management tool, and an evaluation device for monitoring student progress (Lytle & Bordin, 2001). It is designed to assist not only students with disabilities but also the teachers and parents. Through the PPP

process teachers can monitor the educational development of students with disabilities (Ontario Ministry of Education, 2000). One of the most important functions of the PPP is that it serves as a vehicle for communicating among teachers, parents, and other educationally focused professionals (Strickland & Turnbull, 1990).

The PPP team often consists of core team, an in-school team, and an educational support team (Goldstein, Strickland, Turnbull, & Curry, 1980; Manitoba Minister of Education Training and Youth, 1998). Teachers, parents, and the student comprise the core team. The teachers possess the knowledge of the curriculum and a developmental framework within which it is implemented. The teacher also provides instructional expertise on a daily basis to the student. The parents or caregivers bring an in-depth knowledge of the students, including such things as their medical history, daily routines, habits, likes and dislikes, and temperament (Lytle & Bordin, 2001). The student brings the unique perspective of their lived experiences, their likes, aspirations, and dislikes.

The in-school PPP team members can consist of the principal, resource teachers, the instructional assistant, and school counsellor. These contributing members provide important information on the needs for and ability to secure educational resources, transition planning from one educational placement to another (e.g., elementary school to secondary school), as well as ongoing instructional support for the student and family.

The educational support team may include expertise in the areas of psychology, speech and audiology, and physical and occupational therapy. These professionals provide diagnostic information that is useful for educational planning, monitoring of success, and revisions to learning objectives. PPP conferences are typically held several times throughout the school year. Most decisions relating to educational programs of a

student with a disability are made via PPP conferencing among school personnel, the parents, and sometimes the student (Houston-Wilson & Lieberman, 1999). The aim of the PPP team is to plan for a particular student and provide the best educational services available (Fiscus & Mandell, 1983; Lytle & Bordin, 2001).

2.3.2 Procedure

The development of a PPP typically follows a five-step process. As the first step, a student who is perceived to be in need of educational support services is assessed. Specialists in reading, psychology, physical therapy, or speech often complete these assessments (Manitoba Minister of Education Training and Youth, 1998). Eligibility for services through educational, health, and other social support venues are then determined. Next, the PPP team is established based upon the identified needs of the student and a meeting is held to review the findings. Additional information on the student's performance is then collected to develop a profile of the student that will form the basis for the PPP. Information such as the student's attendance records, school behaviour, communication skills, learning approaches, mobility, self-concept, and aspirations can be gathered from the parents, former teachers, and the student him or herself. The PPP is then developed and written by the PPP team. Finally, the program is implemented and an annual program review, for the purpose of evaluating the effectiveness of the learning activities toward the achievement of the goals and objectives, is held (Manitoba Minister of Education Training and Youth, 1998; Saskatchewan Education, 1988; Sherrill, 1998; U. S. Department of Education, 2000).

2.3.3 Debating the Utilization of PPPs

Previous research suggests that teachers were not always satisfied with the overall PPP process (Dudley-Marling, 1985; Morgan & Rhode, 1983). For example, a study by Morgan & Rhode (1983), on the attitudes of special education teachers toward the requirement for an PPP and PPP process, revealed that it was too demanding of their time and they received insufficient support from other school personnel in its development. Special education teachers indicated that they could teach just as effectively without the use of the PPP. The special education teachers did state, however, that the PPP process helped them organize their time and its development and implementation could result in greater job satisfaction. Dudley-Marling (1985) also found that the PPP did not usually assist teachers in planning day-to-day instruction and did not qualitatively affect the education of students with disabilities as it did not guide the delivery of services on a daily basis.

Smith & Simpson (1989) evaluated the quality of the PPPs in terms of procedural compliance, substantive content, and the congruency of assessed needs and annual goals for students with emotional and behavioural disorders. The findings suggested that PPP shortcomings were found in a variety of areas, including the dates and duration of services, related services needed, extent of regular education participation, parent involvement, and public agency or district representatives' signatures. This study suggests the value of the PPP remains uncertain within the special education classroom.

From an inclusive education perspective, Giangreco, Dennis, Edelman, & Cloninger (1994) discussed the characteristics of the PPP for 46 students who transferred from separate to inclusive educational environments. They were interested in

identifying themes that affected the fit of the PPP in a general education climate. They found that the PPP was broad, inconsistent, inadequately referenced to the general education context, and often listed goals for staff rather than those for students.

In one of the few studies that addressed the question of the inclusion of physical education on PPPs, Melograno and Loovis (1991) compared the status of physical education for students with disabilities between 1980 and 1988. Approximately 250 teachers completed a 37 item survey covering 7 categories; experience with students with special needs, teaching abilities, attitudes towards students with disabilities, status of disability programming, expressed needs, limitations of learners, and demographics. In 1980, only 7% of the teachers surveyed had contributed to the development of the PPPs for students with disabilities who attended their classes. Although progress was reported, this figure had risen to only 14% by 1988. These findings raise a question about the overall effectiveness of the PPP process in its present form, its role in physical education, and its overall place in the education of students with disabilities.

2.3.4 Parental Involvement

Parental involvement in the planning process for the PPP has long been considered a cornerstone of special education (U. S. Department of Education, 2000). Parents are encouraged to play active roles and be equal partners with educators in decisions related to their children's educational programming. Research has indicated, however, that parents are often allocated to a passive role in the PPP process (Garriott et al., 2000).

Lusthaus, Lusthaus, & Gibbs (1981) investigated parents' positions regarding the roles they play and would like to play in the PPP decision-making process. Parents of children receiving special education completed a questionnaire that measured perceptions of their current and desired involvement in the PPP process. Three parental roles in the decision making process emerged – no involvement, giving and receiving information, and having input into decisions. The study reported that the most common involvement described by parents was predominantly giving and receiving information, whereas their desired involvement was that of having input into the decisions made about their children's education programs.

In an early study, Yoshida, Fenton, Kaufman, & Maxwell (1978) investigated PPP team members' attitudes toward the parents' role at the PPP meeting. In contrast to the findings of Lusthaus et al. (1981) on parents' desired roles, the school personnel believed that parents should be passive participants, giving and receiving information rather than developing and judging programs and finalizing decisions as active participants. In a later study by Gerber, Banbury, & Miller (1986), investigating teacher's attitudes concerning the participation level of parents during the PPP meetings, the majority of teachers surveyed suggested that parents should be given the option to waive their participation in the PPP meeting leaving the professionals to engage in the decision-making process.

A study conducted by Goldstein et al. (1980) addressed the respective roles of members of 14 PPP conferences involving mainstreamed children with mild learning problems. The primary participants in the PPP conferences were parents, resource teachers, and classroom teachers. The authors reported that the active role of parents was

undermined as resource teachers directed comments *to* the parents or the special educators took the initiative and reviewed the *already developed* PPP on behalf of the parents. And yet, these parents responded positively to a question concerning their satisfaction with the PPP conferences. This finding could be explained by inferring that the parents lacked knowledge of the purpose of the PPP meeting or their role within it, or that they trusted the decisions made on their children's behalf even though they did not participate in the decision-making process.

Gilliam & Coleman (1981) also conducted a study based on the roles of respective PPP members. The purpose of the study was to determine which roles were perceived as most important to the PPP process, which were most influential in decision-making, and which contributed the most to decisions reached at the PPP meeting. Results indicated that parental and administrative roles were perceived as important roles to the PPP process, but that instructional and diagnostic roles were perceived as most influential and contributed to most decision-making in the process.

Salembier & Furney (1997) explored parent perceptions of their involvement and level of satisfaction with their children's PPP meetings. Two-thirds of the 36 parents who were interviewed expressed satisfaction. They stated that they were given the opportunity to talk, to listen, and to ask and answer questions. However, the responses of the 30% of the respondents who expressed dissatisfaction with the process mirrored earlier studies. The parents indicated that they had poor relationships with professionals, lacked information about the planning process, and believed that professionals exerted excessive control over the process.

Garriott et al. (2000) also conducted a similar study on parental involvement and satisfaction in the PPP planning conference. Researchers used both a questionnaire and open-ended questions. They asked about parents' attendance in the PPP conference, their role as a PPP team member, and their role in the decision-making process. Eighty-nine percent of the parents stated that they always attended their children's PPP conferences, but few were attended with their spouses or partners because of scheduling problems due to work, marital status, and/or mothers assuming the major responsibility for the child. Generally, parents were encouraged to actively participate. The parents, however, still remained as recipients of information rather than providers, even though parents expressed high levels of satisfaction with their involvement in their children's educational planning process. The parents indicated that they always were treated in a fair and equitable manner.

In summary, the PPP process developed out of the need for individualization, planning and accountability of educational programming for students with disabilities. Over time, teachers of special education expressed concern about the efficacy of the PPPs in their day-to-day teaching given the time and resource demands placed upon them. When the PPP process was taken into the general education setting, the efficacy of the PPP process was questioned further. Parents have been regarded as integral to the PPP process and yet in practice teachers do not always include parents in the decision-making process. Specific curriculum areas for school subjects are seldom addressed in PPP, including physical education. Mixed degrees of satisfaction have continuously been evident in the literature by parents. Although the parents were appreciative of the opportunity to be involved in the PPP process and learn more about their children's

programs, some parents felt more input into the decision making process was needed.

Given the dissatisfaction that has surrounded the use of the PPPs, how do parents stay abreast of their child's educational needs and communicate their expectations to the school? What mechanisms have replaced the PPP process for teachers if any, and how satisfied are parents with the current role they play in their child's education? There are many unanswered questions surrounding the inclusive educational experiences of children with disabilities.

2.4 Purpose of the Study

Although the importance of parents' roles in the PPP process of their children (e.g., partners, collaborators, problem solvers, observers, mentors, and informants) (Erwin & Soodak, 1995; Gerber et al., 1986; Yoshida et al., 1978) has been documented, few studies have focused on specifically physical education (Downing & Rebollo, 1999). Therefore, the purpose of this study was to gain an understanding of parents' perspectives of their children's experiences in inclusive physical education. More specifically, this study describes a) the value parents placed on physical education for their children; b) the meaning they ascribed to their children's physical education experiences; c) the role of the PPP in parent's communication with the school, and d) the other means of communication parents used to share their thoughts about their children's participation in physical education.

2.5 Conceptual Framework

Theory can be defined as a hunch, a set of concepts, a speculation, or even a guess, that when considered in terms of interrelationships, may explain a given phenomena or observed reality (Palys, 1992). Within the framework of qualitative inquiry, *theory* can play two roles (Morse & Field, 1995). “In qualitative, inductive research, the researcher examines the data for patterns and relationships and then develops and tests hypothesis to generate theory or uses developed theories to explain the data” (p. 4). For the proposed study, theory will be used to facilitate the interpretation of the data.

Many models illustrating disablement have been introduced in the literature (e.g., Nagi, 1965; Peters, 1996; Verbrugge & Jette, 1994). The term disablement describes how the consequences of trauma, disease, and disorders affect functioning of specific body systems fundamental to physical and cognitive actions (Verbrugge & Jette, 1994). Previous models have presented the negative consequences of disease and impairment as defined by modern medicine and reflect changes in ability to complete activities of daily living, dependency upon others, and a decrease in quality of life (Hughes & Paterson, 1997). Recent models, however, have emphasized the significant interaction between impairment/disability, environmental and social contexts, thereby shifting debates about disability from biomedically dominated agendas to ones of citizenship representing the voice of disability (Lawrence & Jette, 1996).

Peters’ (1996) model of disablement emphasizes both the objective (disability observed) and subjective (disability experienced) features of impairment and the impact of not only the biological manifestations of impairment on function, but the role that

society can play in the production of disability. This framework is organized around three perspectives; the outsider, the interventionist, and the insider (see Figure 2.1).

The *outsider* perspective is characterized by objective descriptions of disablement such as those found in research journals, textbooks, diagnostic reports, and classification systems, including sport. For example, "...lower limb paralysis is an instance of motor impairment. This classification can be made based on observation alone; no other details about a person's life are required to classify this impairment" (Peters, 1996, p. 596). Policy makers, researchers, and physicians would be considered to be outsiders.

The *interventionist* perspective goes beyond the abstract objective knowledge that is characteristic of the *outsider* perspective. In this instance, the knowledge is applied in concrete ways with the goal of enhancing the individual's quality of life. The interventionist uses the knowledge of the change in structure and function brought about by disease process, medical condition, or impairment to intervene and maximize the person's existing abilities. A teacher, instructional assistant, or rehabilitation therapist acts as an *interventionist* when the structure and function of the body of the individual is viewed within a social support context.

The *insider* perspective represents that of the person with the disability and integrates the subjective experience of disablement with environmental and social contexts. "The experiencing individual understands disablement against the unique background of his or her body and mind, person, and social world" (Peters, 1996, p. 597). People living the reality of disability reveal their personal meanings of disablement. The impact of the impairment or disorder is experienced through the body and mind and

ultimately is reflected in the individual's sense of personal integrity. The larger context within which a person experiences his or her body and full spectrum of personhood is reflected in the societal context. What is considered to be abnormal from an outsider's perspective may be the reality of daily life and be normal to the person's reality. The social context determines the constraints and affordances that emerge from physical environments, attitudes, cultural norms, and policy.

Peters' (1996) disablement model provides a valuable heuristic framework from which to interpret the data of this study. Parents, according to his model would be considered to be *interventionists* as they continually work to provide the best opportunities and experiences for their children. Parents also communicate frequently with other *interventionists* through the school systems concerning their children's educational programming. Parents of children with disabilities, it can be said, also become experts at interacting with *outsiders* as they traverse the medical system and interpret this information for others.

Outside of the children themselves, the parents come as close to the *insider* perspective as is possible for children with physical disabilities. Parents are often asked to represent their children's interests and through their interpretation of their experiences, tell a story that informs teachers, instructional assistants, and other educational specialists.

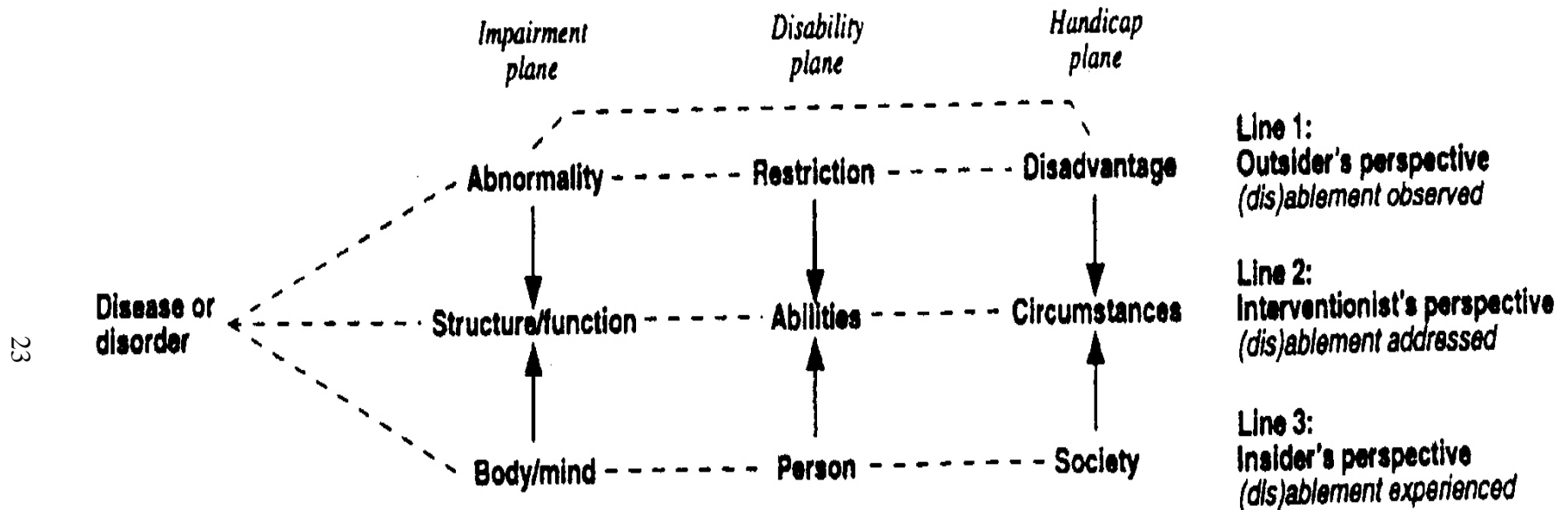


Figure 2.1 Perspectives on disablement (Peters, 1996, p. 596).

Line 1 represents the outsider's perspective, or categories used for (dis)ablement observation. Line 2 represents the interventionist's perspective, or foci of intervention. Line 3 represents the insider's perspective, or (dis)ablement experienced and the contexts of experience. Note that these perspectives are organized across three planes of (dis)ablement. Arrows are explained in the text.

3. METHOD

3.1 Research Design

In order to understand the importance of physical education for students with physical disabilities from the perspectives of parents, it was necessary to provide an opportunity for them to tell their stories. The process of understanding the nature of their day-to-day experience invites naturalistic or qualitative inquiry. Qualitative research is a defined collection of approaches to inquiry relying on verbal and auditory data, often in the form of transcribed from audio-tapes. Video tapes, written records, field notes, and pictures can also be utilized (LeCompte & Preissle, 1994).

Qualitative research focuses on phenomena that occur in natural settings and explores a social or human problem (Creswell, 1998). According to Denzin & Lincoln (2000):

Qualitative research is multi-method in focus, involving an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them. (p. 3)

Phenomenology as a qualitative approach seeks to elucidate the meaning of day-to-day human experiences (Streubert & Carpenter, 1995). Wagner (1983) described phenomenology as follows:

Phenomenology is a way of viewing ourselves, or viewing others, and of viewing all else that comes in contact with our lives. In this sense, it is a system of interpretation that helps us perceive and conceive ourselves, our contact and interchanges with others, and everything else within the realm of our experiences. (p. 8)

Through phenomenological research we deepen our understanding of the nature or meaning of daily experiences. The approach involves the processes of intuition, description, reflection, and interpretation (van Manen, 1997). The central focus of the phenomenological study, therefore, is to describe and interpret "...the meaning of the lived experience for several individuals about a concept or the phenomenon" (Creswell, 1998, p. 51).

According to the writing of van Manen (1997), the approach taken to the study was also hermeneutic. The study was phenomenological because it sought to describe a phenomenon as it appeared to the parents (i.e., the phenomenon of inclusion in physical education) but also hermeneutic in that the stories were told through the language of the parents. To capture the meaning of spoken language requires interpretation given the subjective, non-neutral, and relational quality of words. Stated differently, the approach used was hermeneutic because "there are no such things as uninterpreted phenomena" (p. 180).

Hermeneutics is a method of inquiry in the human sciences that strives to understand or comprehend meaning of the written word (Allen & Jensen, 1990; Allen, 1995). It focuses on interpreting a text or work of art, but in the larger context of qualitative inquiry, it has come to include interpreting interviews and observed actions (Patton, 2002). According to the statement of Allen & Jensen (1990), "...the purpose of hermeneutic description and explanation is to achieve understanding through interpretation of the phenomena under study." Hermeneutical interpretation seeks to construct an animating, evocative description of the human actions, behaviours, intentions, and experiences as we find them in the day-to-day world (van Manen, 1997). The discourse of meaning through this approach is a combination of description, thematic interpretation, and metaphoric insight (Ray, 1994). A hermeneutic approach requires openness to the data (text), the artful interplay of the data and the intuition of the researcher, and the interpretive frameworks that are brought to stand on the analysis of the text (McAuley, 2005). Thus, a hermeneutic phenomenological approach was relevant to this study which sought to understand how mothers of children with spina bifida perceived their children's experiences in inclusive physical education programs.

This study was bound by the ethical guidelines set out by the Behavioural Research Ethics Board of the University of Saskatchewan for studies involving human participants in the social sciences. Ethics approval was granted on May 12, 2003. The participants indicated their consent to use photographs for research and educational purpose by checking the appropriate box on the consent form (see Appendix B). Pseudonyms have been used to protect the identity and confidentiality of the participants.

3.2 Sampling Strategy

Qualitative research focuses on relatively small samples that are purposefully selected to permit understanding of a phenomenon in-depth and to maximize discovery of patterns that emerge from the particular context under study (Erlandson, Harris, Skipper, & Allen, 1993). According to Patton (2002):

The logic and power of purposeful sampling lie in selecting information-rich cases for study in depth. Information rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the inquiry. (p. 230)

The meaningfulness and insights generated from qualitative inquiry have more to do with the information-richness of the cases selected and the observational/analytical capabilities of the researcher than with sample size (Patton, 2002). The sample size recommended by Duke (1984) for phenomenological studies is typically between 3 to 10 (as cited in Creswell, 1998).

In purposeful sampling, the appropriateness of the sampling strategy should be judged on how well the selected sample will facilitate the answering of the research question. A homogeneous sampling strategy was utilized in this study. Homogeneous sampling involves capturing and describing themes that are central to the experiences of a subgroup. A homogeneous sampling reduces variation amongst the participants and simplifies analysis (Patton, 2002). This strategy also permitted the investigator to “control” a condition, experience, or characteristic, in this instance the nature of the disability (spina bifida) and the experiential context of physical education. The

homogeneous nature of the participant sample also facilitated the transferability of the results to other parents who share similar life situations (Meadow & Morse, 2001).

There is tremendous diversity in the nature and abilities of children with physical disabilities who attend school physical education programs. Children may present with neurological impairments such as cerebral palsy or muscular dystrophy. Alternately, children may have spinal cord impairments that cause lack of sensation, muscular weakness or paralysis, as is the case with spina bifida or spinal muscular atrophy. Children may also have missing limbs due to amputations caused by acute trauma, congenital impairments, or cancer. Due to the differences in life experiences, children with different physical disabilities and their families may experience physically, socially, and emotionally different. This study was delimited to mothers, whose children with spina bifida attended inclusive physical education programs. Mothers were defined as birth mothers or other significant females who had full time primary care responsibilities for their children (e.g., grandmother).

A homogeneous subsample of mothers permitted an in-depth understanding of their children's experiences in inclusive physical education. This is not to suggest that fathers do not play active roles in the educational programming of their children. According to the literature, however, mothers play a more active role in the day-to-day school activities of their children (Garriott et al., 2000). It has also been demonstrated that mothers of children with disabilities also take the lead role in the PPP process (Goldstein et al., 1980; Harry, Allen, & McClaughlin., 1995; Salembier & Furney, 1997). The reasons cited for their involvement included scheduling problems, marital status, and mothers assuming primary responsibility within families for children's care.

Spina bifida represents one of the highest incidence of orthopedic impairments in school age children (Sherrill, 1998). It is “a congenital defect of the spinal column caused by failure of the neural arch of a vertebra to properly develop and enclose the spinal cord” (Sherrill, 1998, p. 559). Spina bifida lesions at the thoracic or lumbar region result in loss of muscle control and sensation below the trunk. As a result, children with spina bifida with this level of lesion are non-ambulatory and require the use of a wheelchair for mobility. Children who use wheelchairs present particular challenges to teachers of physical education, as considerable adaptation is required in the interpretation and implementation of the physical education curriculum (The National Education Steering Committee of the Moving to Inclusion Initiative, 1994).

The age range of the children reflects elementary and secondary school physical education experiences. According to the curriculum of Saskatchewan Education (1999), elementary physical education intends to teach physically active lifestyles and movement concepts and principles. The goals of secondary physical education are to provide an opportunity to develop an optimal level of physical fitness and motor skill development through activity components. Due to the different perspectives in the goals of elementary and secondary physical education, it was necessary to listen to the stories of both mothers of elementary and secondary school aged children.

3.3 Participants

The participants were recruited from Saskatoon and surrounding area with the support of the Spina Bifida Association of Saskatoon and the Kids...in Motion Dance team, which was designed for children with mobility challenge whose primary mode of

transportation is the wheelchair, at the University of Saskatchewan. The executive director of the Spina Bifida Association and Director of Kids...in Motion Dance Team were contacted and the nature of the study was explained to them. Both contact people agreed to share the information with their respective parent members and to generate a list of potentially interested families. A package of information including a brochure explaining the study (see Appendix C), eligibility to participate and a copy of the consent form (see Appendix D) was subsequently sent to the respective contact people, who in turn contacted the families. The contact information for nine families was subsequently made available. Seven of the nine families agreed to participate. Two families declined due to busy schedules. Eligibility criteria for inclusion in the study included that:

1. the families had been involved in PPP process that resulted in a written PPP plan current to the previous school year,
2. their children had been active members of the regular school physical education program for at least 2 years,
3. the children's primary form of mobility was a wheelchair due to spina bifida,
4. the children were between approximately 7 and 15 years of age or approximately grades 2 to 10, representing the experiences of the elementary school and high school curriculum and generalist and specialist physical education teachers, and
5. mothers of boys and girls were represented.

The participants completed a Participant Information Form (see Appendix E).

The information is summarized in Table 3.1. Information pertaining to the school

programs and participation in community-based physical activity programs are found in Tables 3.2 and 3.3 respectively.

Six mothers and one grandmother (all primary caregivers) of children with spina bifida were involved in the study. Four participants had children who were in elementary school and 3 participants had children who were in high school. There was 1 boy and 3 girls in the elementary school and 2 boys and 1 girl in the high school. The average age of the elementary aged children was 9.5 years (range 8 to 12) and the average age of the high school children was 14.3 years (range 14 to 15). Two children, Lisa and Andy, were not at chronological grade level because their medical needs resulted in lost time at school. Also, Helen, mother of 9-year old Lisa, was concerned about her child's social maturity so she requested the daughter spend two years in kindergarten. All of the children had at least one sibling. Four of the mothers were employed outside the home (2 part-time and 2 full-time). Three participants completed high school, two participants earned a college degree, one participant obtained a nursing diploma, and one participant completed grade 9.

Table 3.1 Description of Participants and their Children

| FEMALE PRIMARY CAREGIVERS | | | | | CHILDREN | | | | |
|---------------------------|--------------------|-----------------|-----------|----------------|----------|-----|-------|------|------------------------|
| Name | Occupation | Paid Employment | Education | Marital Status | Name | Age | Grade | Sex | Siblings & Age |
| Helen | Retail Manager | Full-Time | Grade 12 | Married | Lisa | 9 | 2 | Girl | Brother 11 |
| Erin | Caregiver | N/A | College | Married | Rebecca | 8 | 3 | Girl | Sister 5 & 11 |
| Bonnie | Nurse | Part-Time | College | Married | Andy | 9 | 3 | Boy | Sister 6 |
| Andrea | Executive Director | Full-Time | College | Partner | Julie | 12 | 6 | Girl | Sister 17 & Brother 19 |
| Kim | Caregiver | N/A | Grade 9 | Divorced | Megan | 14 | 9 | Girl | Sister 16 |
| Margie | School Bus Driver | Part-Time | Grade 12 | Married | Dustin | 14 | 10 | Boy | Sister 14 |
| Jeanette | Caregiver | N/A | Grade 12 | Married | John | 15 | 10 | Boy | Sister 17 |

The scheduling of physical education for the elementary and high school programs was different (see Table 3.2). In the elementary schools, the physical education programs were held two and three days per week with the exception of Julie's school where daily physical education was implemented. The high school physical education programs ran five days per week during one semester only. The elementary physical education programs were taught by classroom teachers except for Rebecca's school, which was taught by a physical education specialist. The high school physical education programs were taught by physical education specialists. Elementary students received the support of a full time teacher associate (TA) in physical education. Although the high school students had part time teacher associate support, the TAs did not attend physical education. All gymnasium facilities were fully accessible to wheelchairs.

The PPP meetings were held twice per year, at the beginning and the end of school year, except for Andy's school. His school had four meetings during the school year. The members of the PPP meeting generally consisted of the principal, classroom teacher, special education teacher, teacher associate, and parents. For only two of the seven families did the student participate in the meeting. The physical education specialists were not involved in the PPP process. Depending upon the needs of the student, other professionals may have attended the PPP meetings (i.e., nurse, speech pathologist).

Table 3.2 Physical Education and PPP Information

| PHYSICAL EDUCATION | | | | PERSONAL PROGRAM PLAN | |
|--------------------|----------------------|------------|-------------------|-----------------------|---|
| Children | Classes/week | Teacher | Teacher Associate | Meetings /year | Members |
| Elementary | | | | | |
| Lisa | 2~3 | Classroom | Yes | 2 | Principal, Classroom, Special Education Teacher, TA, School nurse, Physical Therapist, Mother |
| Rebecca | 2 | Specialist | Yes | 2 | Classroom, Special Education Teacher, TA, Mother and Father |
| Andy | 2~3 | Classroom | Yes | 4 | Principal, Classroom, Special Education Teacher, TA, Speech Pathologist, Mother and Father |
| Julie | 5 | Classroom | Yes | 2 | Classroom, Special Education Teacher, TA, Mother and Father, Child |
| High School | | | | | |
| Megan | Daily for 1 semester | Specialist | No | 2 | Special Education Teacher, TA, Grandmother |
| Dustin | Daily for 1 semester | Specialist | No | 2 | Special Education Teacher, Mother and Father |
| John | Daily for 1 semester | Specialist | No | 2 | Special Education Teacher, TA, Mother and Father, Child |

All of the children were involved in community physical activity programs at the time of study (see Table 3.3). Their average years of participation were 5.4 years (range 3 to 10). Four of the children participated in disability programs and the remaining three children participated in both disability and inclusive physical activity programs. The most common programs were swimming and wheelchair sports.

Table 3.3 Participation in Community Physical Activity Programs

| Name | Years of Involvement | Disability Sports | Community Programs |
|---------|----------------------|---|-----------------------|
| Lisa | 3 | W/C Dance, Swimming | No |
| Rebecca | 5 | W/C Dance & Basketball Swimming | No |
| Andy | 5 | W/C Dance, Tennis, & Basketball Swimming | No |
| Julie | 7 | W/C Dance, Skiing, Swimming | Swimming, Dance |
| Megan | 5 | W/C Racing, Tennis,& Basketball Skiing, Swimming | No |
| Dustin | 10 | W/C Basketball, Skiing, Swimming | Basketball, Wrestling |
| John | 3 | W/C Basketball & Rugby, Swimming | Bowling, Soccer |

W/C = Wheelchair

3.4 Data Collection

There are four general sources of information that researchers utilize in qualitative research: (a) transcribed interviews (unstructured and semi-structured), (b) observation (field notes), (c) artifacts (visual materials), and (d) documents (report cards, newsletters, and meeting agendas) (Bogdan & Biklen, 1998; Creswell, 1998; Erlandson et al., 1993; Patton, 2002). The combination of several data sources brings multiple perspectives forward and allows the researcher to better understand the essence of the experiences encountered (Erlandson et al., 1993). Information for this study was collected through interviews, visual artifacts, documents, and field notes.

3.4.1 Interviews

Interviewing is one of the most common and powerful methods that can be used to understand human experiences (Fontana & Frey, 1994). Seidman (1998) states, “it is a privilege to gather the stories of people through interviewing and to come to understand their experience through their stories” (p. xxi). The purpose of qualitative interviewing is to understand others’ meaning making (Warren, 2002). Interviews can take various forms, ranging from those that are focused or predetermined to those that are very open-ended, where nothing is set ahead of time (Dunn, 2000; Erlandson et al., 1993). For example, semi-structured interviews use predetermined but open-ended questions, with an expectation of a broad range of responses. Unstructured interviewing focuses on personal perspectives and histories, so the questions are completely determined by the interviewee’s responses (Dunn, 2000; Fontana & Frey, 1994).

A semi-structured interview format is consistent with phenomenology (van Manen, 1997) and was therefore utilized for this study. As the research question was seeking to gather information about an area that has received relatively little research attention and the perspective of mothers who share common experiences was desired, the semi-structured format was well suited to this investigation. Although semi-structured interviews begin with a framework provided by predetermined open-ended questions, additional questions can be asked over the course of the narrative between the interviewer and the interviewee. In essence, the interview is guided by a set of basic questions and issues to be explored, but neither the exact wording nor the order of the questions is predetermined (Erlandson et al., 1993). The interview guide was sent to the participants ahead of time to give them opportunity to think about the question prior to the interviews. A copy of the interview guide appears in Appendix F.

All but one of the participants took part in 2 one-on-one semi-structured interviews lasting approximately 45 to 60 minute each. One mother did not complete the second interview due to time constraints. The focus of the initial interview was on understanding mothers' perspectives of their children's experiences inclusive physical education program. The second interview focused on understanding the means of communication mothers used to share their thoughts about their children's participation in physical education. During the second interview, the participants were also asked to explain the significance of artifacts and documents they provided (photos and PPP documents as described below).

All of the interviews were conducted in a mutually agreed upon location, free from distractions, over a six month period by the investigator. The interviews were

recorded by a standard tape recorder during each interview. The investigator transcribed the audio tape verbatim prior to each successive interviews to identify patterns and issues that needed clarification (Seidman, 1998).

I began each initial interview by sharing my personal background. I told them where I came from, why I came to Saskatoon, Canada, what I did in my past, and why I was interested in this study. In doing so I established rapport with the participants. As this was the first research study, the results and their interpretation must be read within the following context:

- (a) My background in interviewing was limited graduate course work,
- (b) English is not my first language. I was born and raised in South Korea,
- (c) I was unknown to the participants prior to the study,
- (d) The families provided the interview time amidst very busy schedules.

3.4.2 Visual Artifacts

Qualitative inquiry can utilize photography and videography as an information source. A picture is ‘worth a thousand words.’ Photographs may help recall events that have happened and also capture the setting so as to provide ‘a sense of the physical environment’ (Patton, 2002). Further, photographs can also present specific factual information that can be used in conjunction with other sources. Moreover, when analyzed, photographs can provide descriptive data, thereby adding to the existing evidence (Bogdan & Biklen, 1998).

The parents were asked to share photographs that helped explain their thoughts, feelings, and knowledge about their children’s experiences in physical education.

Suggested images were school activities, physical education classes, and community physical activities. The parents were asked to bring the images to the second interview where they served to stimulate discussion (Patton, 2002). The participants explained the photo's significance in the interview, thereby adding to the textual record. With the permission of the participants, the photos were scanned so that a permanent record was available for purposes of data analysis and write up.

3.4.3 Documents

Documents represent a broad range of written and symbolic records and can be categorized as personal, official, and popular culture documents (Erlandson et al., 1993). Specifically, documents are such items as letters, diaries, memos, works of arts, meeting agendas and notes, and news releases. These sources of information can be used to supplement interview and observation data and add to the trustworthiness of the findings (Bogdan & Biklen, 1998). Documents also provide both a historical and contextual dimension to the study (Glesne & Peshkin, 1992). Therefore, participants were asked to provide PPP documentation (see Appendix A) and other school documents (i.e., student report card and daily home-school communication notes). As with the photographs, the parents were asked to bring the documents to the second interview and the documents were utilized to stimulate discussion. Copies of the documents were made with the permission of the parents for later reflection. Asking the participants to describe their experiences with the aide of documents and photographs added depth to the record of evidence and helped to remove researcher bias from the interpretation of the materials (Patton, 2002).

Three different documents, including student report cards, individual communication notes, and PPPs were provided by participants. Four mothers provided the student report card in the second interviews (2 elementary & 2 high schools). Helen, mother of 9-year-old Lisa, brought a note which was used to communicate with Lisa's TA. Five of seven participants provided PPP documentation. All the mothers of children in elementary school provided PPPs as did one mother of a child in high school although it was from elementary school as she could not find the most current PPP.

Although one of the program goals (#7, see Appendix A) that outlined the PPP specifically relates to objectives, strategies/ resources and progress for Motor Development, only two of the 5 PPP documents provided by the parents included information specific to the physical education program. Examples of the type of information included under the goal of motor development were as follows: "To improve and maintain strength and stamina," "To participate in cross-country skiing with the class" (Julie, age 12). "Adapt gym activities so that Andy can participate as much as possible (e.g., floor hockey & basketball)" (Andy, age 9).

3.4.4 Field Notes

Field notes are the written accounts of what the researcher hears, sees, experiences, and thinks in the course of collecting and reflecting upon the data in a qualitative study (Bogdan & Biklen, 1998). According to the definition of Schwandt (2001), field notes are "a kind of evidence on which inquirers base claims about meaning and understanding" (p. 96).

Field notes were taken after the interviews. The researcher recorded reflections about what was said that day, ideas for further probing with subsequent participants, and preliminary thoughts about themes that were emerging from the data. These notes permitted the investigator to conceptually return to the setting during the analysis of the data (Jackson, 1990).

3.5 Data Analysis

Data analysis is the process of organizing data, of conjecture and verification, and of correction and modification (Morse, 1994). Qualitative research is a process of systematically searching and arranging the interview transcripts, field notes, and other materials (Bogdan & Biklen, 1998). Phenomenological analysis, in particular, seeks to grasp and explicate the meaning, structure, and essence of the lived experience or phenomena for a person or group of people (Patton, 2002).

To analyze the meaning, structure, and essence of the participants' experiences, a thematic line-by-line analysis of the interview data was completed (van Manen, 1997). Thematic analysis identifies common structures of the particular experiences under study and is the primary mechanism by which understanding is achieved (Morse, 1994). It entailed reading the interview transcripts and field notes numerous times. Particularly, revealing phrases were highlighted and coded with meaningful labels. Codes that are conceptually similar were gathered together into thematic statements, giving fundamental meaning to the experiences (Patton, 2002).

The data were analyzed separately by age group (elementary and high school). The essential themes that emerged from the data were similar for both groups, although

some distinctions were evident within the experiences of the two groups given the concept-based skill emphasis of the secondary physical education program. These distinctions will be highlighted in the results and subsequently explored in the discussion. Although the findings were not analyzed by gender specifically, meaning that the transcripts were read carefully for differences that may have been expressed by caregivers of sons or daughters. This was possible given the small, yet in-depth size of the participating sample. No differences were noted between the experiences of mothers who had sons or daughters.

The documents and artifact information were analyzed in a manner similar to the interviews. During the second interview, the participants discussed the material they brought with them in detail and the recorded information became part of the textual transcript records.

3.6 Trustworthiness of Qualitative Research

The goal of qualitative research is not to produce generalizations but rather generate in-depth understandings of particular phenomena (Leininger, 1994). Therefore, research rigour should be evaluated using different criteria from the positivist constructs of internal and external validity, reliability, and objectivity (Lincoln & Guba, 1985). Lincoln & Guba (1985) suggest the trust value of qualitative research can be enhanced through attention to credibility (or verification), applicability through transferability, consistency through dependability (or validation), and neutrality through confirmability. The strategies undertaken to maximize trustworthiness within this study were summarized in Table 3.4.

Triangulation is defined as “the attempt to arrive at the same meaning by at least three different independent approaches” (Johnson, 1992, p. 90). It increases the probability that the findings and their interpretations are a true reflection of the participants’ experiences (Lincoln & Guba, 1985). Triangulation can occur numerous ways, including methodological triangulation (e.g., interview, observation, documents, photographs & videograph), data triangulation (e.g. interview respondents), investigator triangulation (e.g. single or multiple investigators), and theoretical triangulation (use of multiple perspectives to interpret a single set of data) (Janesick, 1994; Lincoln & Guba, 1985). Within this study data, the investigator employed methodological (e.g., 2 one-on-one interviews, artifacts, documents, and field notes), data (e.g., mothers who have daughters and sons, elementary and high school), and investigator triangulation were implemented. The investigator’s supervisor collaborated on the analysis and interpretation of the data.

Table 3.4 Trustworthiness Strategies

| Trustworthiness Criteria | Application to Study |
|---|--|
| Credibility or Verification <i>Truth Value</i> | Data Saturation Data Triangulation Purposeful Sampling Researcher Credibility |
| Transferability <i>Applicability</i> | Thick Description Homogeneous Sampling Strategy |
| Dependability or Validation <i>Consistency</i> | Audit Trail Member Checks Multiple Data Sources |
| Confirmability <i>Neutrality</i> | Investigator Triangulation |

Credibility (or verification) refers to the “truth value” of the findings (Meadow & Morse, 2001). Credibility has been addressed within the design of this study in the following ways:

- The interviews continued until it was felt that data saturation was reached. When the researcher feels that there is repetition occurring in the narratives of the participants and the stories shared by later participants begin to confirm earlier interviews, then saturation has been reached.
- Data triangulation was undertaken. The interviews of mothers of sons and daughters of elementary and secondary school age were returned to

repeatedly. The descriptions of the experiences were checked against the documents and photographs to provide further corroboration to the understanding that emerged.

- Careful purposeful sampling was undertaken. By working diligently to ensure that the participants meet all of the stated criteria with the help of the recruiting agency, credibility was enhanced.
- In qualitative inquiry, the investigator is the primary instrument for the collection and analysis of data. As a former physical education teacher for children with physical disabilities, I had a strong background in inclusive physical education. I often communicated with parents about the physical education program and their children's programs. Although not a mother myself, I tried to see the situation from their viewpoint.

Transferability refers to whether particular findings from a qualitative study can be transferred to another similar context or situation and still preserve the particular meanings, interpretations, and inferences from the completed study (Leininger, 1994). Although qualitative research cannot claim empirical generalization, naturalistic transferability can appear through the proper use of thick description to dispel the typicality of the sample (Lincoln & Guba, 1985; Mason, 1997). Transferability was established in the following ways:

- A description of each family setting was undertaken to provide context to the experience. Such descriptions strive to state everything that the reader may need to know in order to understand the findings (Erlandson et al., 1993).

Investigator has described the participants in detail. In addition to information on the age of their children, their physical function, likes and dislikes and, physical activity interests was gathered. This information provided a foundation for recognizable congruence of these parents' experiences within other contexts (Denzin & Lincoln, 2000). Background information was summarized for each family (see Tables 3.1, 3.2, and 3.3)

- A homogeneous sampling strategy was undertaken. Recruiting a particular subgroup (i.e., parents of children with spina bifida) facilitates naturalistic generalization or the degree to which two contexts are similar (Lincoln & Guba, 1985).
- The transferability or fittingness of the findings beyond the experiences described by the parents of this study was also enhanced by using participant quotes to illustrate the themes.

Dependability (or validation) refers to a study's consistency or the soundness and accuracy of the findings. To provide a check on dependability, the researcher must provide evidence of an external check on decision making process conducted throughout the design of the study and its implementation (Meadow & Morse, 2001).

- The researcher completed an audit trail, which is a written record of the research process (Meadow & Morse, 2001). The written records included the researcher's decisions, choices, and insights. The audit trail is a "technique that permits research validation by allowing another investigator to follow the cognitive development of a project as it developed" (Morse, 1994, p. 24).

During the process, the investigator recorded field notes that produced the description of research setting and procedures, such as recruitment, interview dates, and notes that information sent out to research participants. All methodological decisions made throughout the study were recorded.

Analytical notes were made to provide a record of thought processes of the investigator in sorting and categorizing data and in conceptualizing patterns that emerge during analysis. In addition, the investigator had regular meetings with her supervisor. The investigator's supervisor completed an external audit by meeting regularly and communication on email along with committee members during face-to-face committee meetings and email communication over the course of the thesis process.

- A member check was completed. All participants were asked to confirm or correct the reconstruction of their idea and experiences (Lincoln & Guba, 1985). Member checks are an opportunity to share opinions, reactions, and descriptions and for the researcher to examine the reflection of participants on the work done by the researcher as a source of information on the topic (Meadow & Morse, 2001). Additionally, it is imperative both data and interpretations obtained be verified by participants because the findings have individually and collectively been constructed by persons within the context of the study. The member checking was completed in 2 phases. After the interview data was transcribed, the investigator mailed a copy of the transcripts to the research participants. They were asked to review the transcripts for accuracy, send any changes back, and return the signed

transcript release form. The mailed out information was followed up with a phone call. All participants returned the signed transcript release forms. One participant made a change to the transcripts, to increase clarity to what she meant to say. In the second phase of the member checks the result of the analysis were mailed to the participants. A cover letter and summary of the themes and their descriptions were sent in a package that also included a reply form with a stamped, self-addressed envelop (see Appendix G). All of the participants returned the forms and indicated that their experiences were reflected in the thematic summaries.

- Multiple data sources were undertaken. In addition to interviews, field notes, visual artifacts, and documents were kept and used to facilitate the analysis and interpretation of the information.

Confirmability refers to the objectivity of the data (Lincoln & Guba, 1985). It is concerned with establishing the fact that the data and interpretations of an inquiry were not merely figments of the investigator's imagination. In addition to the previously mentioned techniques of data and methodological triangulation, confirmability was established by the use of investigator triangulation (i.e., investigator and investigator's supervisor). In addition, the researcher's supervisory committee reviewed the research proposal prior to data collection and provided guidance throughout the research process.

4. RESULTS

Three themes emerged from the thematic analysis of mothers' perceptions of the importance of physical education for children with physical disabilities (a) a good thing but..., (b) connection to disability sports, and (c) beyond the curriculum. The themes are supported by subthemes that further explicate the experiences of the mothers (see Table 4.1).

A Good Thing But... expressed the mothers' feelings that physical education was very beneficial for their children. The health benefits of physical activity as an intervention against obesity brought about by sedentary lifestyles were expressed. The mothers also recognized the important role physical education played in social development, including confidence and self-esteem. Although the mothers recognized the benefits of their children's involvement in physical education, they also expressed concern over environmental, instructional, and curriculum barriers to their children's participation.

*Connection to Disability Sports*² emerged as the mothers indicated how their

² Disability Sport [is] any sport conducted primary for people with disabilities. Term is not used in Special Olympics, which is a worldwide program for people with mental disabilities (Sherrill, C., 2004, p. 759)

children's school physical education experiences helped prepare them for more experiences in community sports for people with disabilities. In turn, the community disability sport experiences resulted in more active participation in selected components of the school physical education program. The link between the school and the community was a mutually beneficial one.

Beyond the Curriculum reflects the role the mothers played in helping others understand their children. They worked to demystify the wheelchair and explain to teachers, instructional assistants, and classmates what spina bifida was. They also were highlighting their children's abilities and how similar their needs were to that of other students.

Each of the three themes and their respective subthemes will be presented in detail, using photographs and direct quotes to illustrate their meaning.

Table 4.1 Summary of Thematic Analysis

| THEME | SUBTHEMES |
|---------------------------------|--|
| A Good Thing But... | Supports development Participation barriers |
| Connection to Disability Sports | Enhanced school participation Developing disability sports skills |
| Beyond the Curriculum | Bringing a different frame of reference Keeping the balance |

4.1 A Good Thing But...

The mothers believed that the physical education program supported the development of their children in a variety of ways. In addition, the mother felt that it was difficult at times for their children to be active members of the physical education class. They expressed concern over the amount of support available to their children. The problems were described as environmental, instructional, and curricular in nature.

4.1.1 Support Development

The participants perceived school physical education to be of benefit to the social and health development of their children, and an important subject in their children's school programs. The development of social skills was recognized in an outcome of physical education. The social benefits included friendships, personal enjoyment, a sense of belonging, and increased self-confidence. They wanted their children to make friends through the participation in physical education. To some mothers, the social and enjoyment benefits were of more significance than the potential for physical skills or health benefits. Helen, mother of 9-year-old Lisa, said, "I just want her to make friends. To me, that's more important than the physical education part of it. Right now, at her age, friends are more important so I guess the feeling is fitting in." Jeanette, mother of 15-year-old John, said, "I think it's [physical education] a sociable thing for him. I mean he can make friends there." Kim, grandmother of 14-year-old Megan, also stated: "It [physical education] is very beneficial for Megan to make friends."

Physical education was perceived to be a subject their children enjoyed at the elementary and secondary school level. It is interesting to note that the mothers perceived their children were enjoying physical education even though they were unsure of the extent to which they were actively involved in some instances. Helen, mother of 9-year-old Lisa, considered having fun as a priority for Lisa's physical education program: "I just want her to have fun, you know. At the same time, she's getting out, she's doing a little bit of exercise, but she's mostly enjoying herself and that's important." Erin, mother of 8-year-old Rebecca, also thought that school physical education was a place where Rebecca could enjoy her time. "For her physical education program, she gets enjoyment out of it. I don't know how much physical activity she actually gets out of it. I just want her to have fun." She thought that the physical education program helped Rebecca to feel a sense of joy:

The day that she has gym... she comes out from school and has a big smile on her face and she says, 'I had gym today' and she'll tell me what she did. She really enjoyed the floor hockey component when they did it because she got a goal, things like that.

Bonnie, mother of 9-year-old Andy, stated:

It's [physical education] important. It's different from the school work. It lets them have fun. Even if he can't participate in activities, he still enjoyed watching it, you know. Even if he can't be a part of it because of physical safety, he still likes to be cheering them on and still can interact with the kids.

Jeanette, mother of 15-year-old John, said, "He's playing with all children and they are all doing something together. That's fun." Kim, grandmother of 14-year-old Megan, concurred, "It [physical education] is good for her because she can get out there joining whatever and she can be with other kids and have fun." Andrea, mother of 12-year-old

Julie, provided a photo of Julie's participation in physical education. Andrea felt the photo depicted her daughter's enjoyment of physical education (see Figure 4.1).



Figure 4.1 Julie enjoying physical education

A further social benefit of physical education perceived by the parents was the sense of belonging that their children experienced in this context. A sense of belonging was reported by parents of children at both the elementary and secondary levels. Erin, mother of 8-year-old Rebecca, recalled:

[Physical education is] very important. I think not only for the benefits of physical education as staying healthy but also just a benefit of being included, you know. I think it is being a part of group and a part of class.

Participation in physical education enabled their children to be with peers without disabilities and be members of a group. Erin shared a photo showing Rebecca's

inclusion in a group activity in physical education highlighting her group involvement (see Figure 4.2).



Figure 4.2 Rebecca in physical education

Helen, mother of 9-year-old Lisa, explained: “She can be with other kids with her own age no matter what. She is a part of it. That’s really important to me.” Bonnie, mother of 9-year-old Andy, also said, “In physical education, the most important thing is to be with other kids and to be a part of group....I think it’s very important for him to feel a part of that.” Andrea, mother of 12-year-old Julie, also stated the importance of being a part of the physical education class:

Julie’s able to be a part of everything that she is capable and desires to be a part. The people who are around her will help to accommodate her disability in terms of adapting that activity so that she can be a part of the group.

Jeanette, mother of 15-year-old John, felt that physical education provided the best opportunity for him to connect socially with other students. “If there were no physical education in school, he would feel set apart from them [classmates].” Kim, grandmother of 14-year-old Megan, spoke of the connection she felt with her classmates during physical education to the extent that the presence of her disability was minimized. “It’s very important because it [physical education] does make her feel that she isn’t different than any other kids.”

The final social benefit of physical education mentioned by the participants was self-confidence. This benefit was only identified by the mothers of girls. They perceived that inclusive physical education inspired their children to establish a positive self. Erin, mother of 8-year-old Rebecca stated: “It [physical education] probably did make and give Rebecca some sense of competence.” Andrea, mother of 12-year-old Julie, also recalled:

The physical education aspect of her school experience has been most beneficial for her self-esteem and development of her own self-confidence. We left our wheelchair at the school, an extra wheelchair, in her physical education class so there is usually one other child, able-bodied child, using a wheelchair as well. So if it’s an activity like ping-pong, badminton, or tennis that there is another child that is playing at the same level as she is. This is been very good for her self-esteem.

Julie’s mother recognized the importance of providing a positive social experience for her daughter in physical education. Making arrangements to leave a wheelchair at the school provided an opportunity for other students to share in some of her daughter’s experiences, thereby building empathy and understanding in others. It also provided her daughter with a “level playing field” for dual activities. This mother

was successful in creating a positive learning environment for her daughter. The wheelchair was actively used in physical education according to Andrea. Andrea successfully communicated her desires and made equipment available, and the school was open to the idea to the betterment of all involved.

All participants perceived health promotion as an important outcome of participation in physical education. Children with spina bifida spend most of their time in their wheelchairs so the amount of physical movement is much less than that of other children without disabilities. Also, as a society we are becoming more and more sedentary as we spend time using computers and watching television (Pangrazi, Corbin, & Welk, 1997). Bonnie, mother of 9-year-old Andy, commented:

It [physical education] helps to teach the importance of being physically active, not sedentary because a lot of the lifestyles nowadays involves sitting in front of a computer and TV. It promotes just keeping active, which is very important.

Margie, mother of 14-year-old Dustin, stated: “I think physical education is important. All kids are overweight today because they go to McDonalds and they sit to watch TV and play games.”

School physical education was recognized as an intervention to the health risks associated with obesity. Obesity was one of the health concerns raised by the mothers. Margie, mother of 14-year-old Dustin, said, “[Physical education is] very important since they’re in wheelchairs a lot of time. They don’t get the exercise that other kids get, like just getting out for walking around...so very important to keep them active.” Kim, grandmother of 14-year-old Megan, and Jeanette, mother of 15-year-old John, also perceived physical education as a means to “keep them healthy.” Erin, mother of 8-

year-old Rebecca, mentioned that physical education helped Rebecca avoid obesity as a secondary impairment to her spina bifida. “I think, because of using a wheelchair you are at risk for secondary type things like the obesity. I think physical education lends a big part to a healthy lifestyle.” Andrea, mother of 12-year-old Julie further stated:

Julie has grown this year... but she is always been kind of on the heavier side because of her height. Her stature is short so we want her to maintain a good level of physical activity and to keep her weight down, you know, to have a good heart, build up her heart, and build up her upper body muscle.

4.1.2 Participation Barriers

Along with the positive views of the physical education programs, the participants also expressed some concerns. Mothers mentioned specific barriers to participate in physical education that their children faced. The barriers described by the participants were related to safety (specific learning activities, facilities), the environment (equipment, wheelchair accessibility), and instruction (curriculum adaptations, knowledge of disability, and availability of support).

The first participation barrier and concern for the parents was safety. Safe participation of their children in physical education was of prime concern to the mothers. Children with spina bifida are predisposed to the health risk of hydrocephalus, which is excessive fluid within the ventricular system of the brain with which can build up and cause inter cranial pressure. Children with spina bifida require surgical placement of cerebrospinal fluid (CSF) shunting devices to drain the fluid from the brain (Duncan & Ogle, 1995). Furthermore, these children have motor paralysis and lack of sensation in their torsos and lower limbs. This means the children are prone to joint and bone injuries caused by impact, compression, or torque forces, as well as the breakdown of

skin due to pressure and poor circulation. Resultantly, mothers are concerned about their children's safety. Margie, mother of 14-year-old Dustin, explained her concern about wrestling due to his shunt:

The wrestling, it bothers me. I didn't like to see pulling on his head. I was a little concerned because the way that they were with the neck. He's [Dustin] got the shunt. I didn't like the way that they were doing on his head.

Helen, mother of 9-year-old Lisa, clearly identified safety as a concern:

They encouraged her to participate in just about everything that she can. I don't have a problem with her participation in physical education as long as the circumstances are not going to put her in danger. I mean if it's a safe activity that supervised then she can go for it. If it's something there, there's possibility she can get injured, I don't want her to go.

The mothers spoke of the risk of serious injury to their children's lower limbs in physical education. Erin, mother of 8-year-old Rebecca recalled an outdoor game that her physical education class played on the hard surface adjacent to the school. The wall of the school was considered to be a safe or free zone. Coming in contact with vertical surfaces placed her daughter in harms way.

I think the only time that physical education is not appropriate would be it is unsafe. When you touched the wall, you were considered a safe or a free. She would run or wheel and her legs would constantly slap into the cement or concrete wall. She can't feel that hurt. Her bones are not as strong as her mind. She can end up the broken bones. When it's not a safe environment, it would be the only time that I would hesitate.

Jeanette, mother of 15-year-old John, discussed the safety risks of using the small gymnasium for all students with and without disabilities. The cramped quarters were perceived to increase the risk of contacting the wall, thereby placing the integrity of

John's lower limbs in jeopardy. The teacher in this instance restricted John's

participation against the student's desire to be involved:

The smaller gym was dangerous for him because he was always hitting the wall. It was dangerous for the other children probably because it is too small. I remember that certain games that the teachers never let him play. He thought he should. But I think they were really worried about the safety, his safety.

She also raised, not a personal safety concern for her son but, the risk posed by the wheelchair to other students in specific physical activity contexts. She was concerned that activities, such as football, where physical contact is expected may place other students at risk of injury by coming in contact with the wheelchair. Jeanette stated:

The wheelchair just doesn't fit, like football. In high school, they're a little rougher in football. In elementary school, it was nothing just to run at the ball. But if you know he can have a wheelchair in the middle of a whole bunch of boys, they all would've hurt themselves too, knocking into the wheelchair.

The mothers explained that their concern for safety was often at odds with the enjoyment their children experienced in physical education. Although scooter board activities have the potential to equalize the abilities of all students. Bonnie, mother of 9-year-old Andy, felt that they were potentially unsafe. Andy has poor sitting balance so without the support of his wheelchair he is at risk of falling off the scooter board. Andy, in contrast, according to his mother, thoroughly enjoyed the activity.

Scooter board that was one that I wasn't very happy about because I didn't feel that there had been a lot of thought went into that. It was very unsafe. Those scooter boards, the one foot by one foot boards, were on wheels that the children sit on. There are a lot of fun for the kids and Andy, of course, thought a lot of fun as well, but so unsafe because he doesn't have any upper body stability right now. They actually let him sit on one of these and it was so unsafe for him.

The mothers acknowledged that their children needed modified equipment to participate in some physical education activities. Jeanette, mother of 15-year-old John, explained: “I think a lot of things are not appropriate because they don’t have the equipment that he would need. If they are doing hockey, he needs a shorter stick.” Sport days and special school outings were especially challenging as it can be difficult to negotiate natural surfaces or keep up with classmates when activities are taken off the school site. In some instances, mothers were able to provide specialized equipment to foster their children’s participation in other instances they were not. Bonnie, mother of 9-year-old Andy, stated:

Today is sport day and they’re having bikes. They will be biking and that kind of stuff, which is wonderful but of course not at all good for him because we would have to provide the bike and we don’t have that, you know.

Some mothers were able to provide the appropriate equipment to support their children’s participation in physical education. They knew what equipment their children would need for specific activities (e.g., sit-ski for cross country skiing, hand-crank cycle for cycling) and where they could obtain the equipment for rent or loan. The families who had their children involved in disability sports programs were knowledgeable about what was needed, and resourceful in their ability to secure the equipment. The schools were always receptive and thankful of the parents’ initiative. Andrea, mother of 12-year-old Julie, said:

If the program didn’t include the equipment that she needs, we worked with the teacher or the resource room teacher, and ourselves to get the equipment for her so that she has an access to the right equipment. For example, skiing, she used a sit-ski so we go to SASK ski. We have to rent that for the year and have to make sure that we get the equipment to the school.

Erin, mother of 8-year-old Rebecca, also stated that she borrowed a hand-crank cycle from her friend who has a spinal cord injury so Rebecca could participate in biking with her peers. The positive social impact of her being able to participate is relayed (shared?) below:

Last week there was a bike safety clinic at school. We [parents] borrowed a hand-crank cycle.... There's a huge hill in a playground where she went. I think everyone was in a shock, you know. They didn't think that she is being able to climb the hill but she certainly did.

Use of wheelchair friendly or accessible spaces was also identified as one of the environmental barriers to participation in physical education. According to the participants, the gymnasiums were accessible, but other learning environments may not have been (e.g., playground, weight room). Jeanette, mother of 15-year-old John, mentioned the weight room in John's school. She was unhappy that John was not able to use the facility because it is only accessible by stairs: "I know several high schools that have a weight room. He can't get there because they're upstairs, no lifts, and no anything."

Not only were there barriers inside the school, but outside as well. Physical education programs are often instructed on the grass playing fields. Grass, as a natural surface, poses an environmental barrier to students who use wheelchairs. It increases the resistance to forward motion due to its soft and textured surface. The physical exertion required to wheel on grass quickly fatigues the student. Andrea, mother of 12-year-old Julie, provided a photo which was taken at the school track meet when she was in Grade 5. She felt that participating in the school track meet with her peers without disabilities was good because she would be doing the same activities and be a part of the group. On

the other hand, grass is wheelchair unfriendly and presented a tremendous physical challenge. She was often left far behind her classmates, leaving her to participate devoid of a social context (see Figure 4.3).



Figure 4.3 Julie at the school track meet

Kim, grandmother of 14-year-old Megan, also described grass as being very difficult for Megan to negotiate. In Megan's case, alternate activities were arranged, although this removed her physically and socially from her classmates: "They would do track on the grass and the wheelchair didn't work very well on that grass so that they would give her something else to do."

The third participation barrier that was meaningful to the mothers reflected the quality of instruction their children received. More specifically, accounts specific to curriculum adaptations, knowledge of disability, and the availability of support were revealed.

Although the mothers were pleased overall with their children's experiences in physical education, they felt that with additional curriculum adaptations, participation would be further enhanced. There was a sense from the parents that active involvement in group activities was difficult and that careful selection of learning activities, modifications or alternate equipment would have been helpful. Bonnie, Andy's mother suggested that Andy's participation occurred when he fit the program (age 9), rather than the program being adapted to fit him. Bonnie recalled:

Right now in the program that they have at school, Andy's just kind of fitted in and slotted in, instead of having some kind of activity. If he'd play basketball, the basketball net hasn't been adjusted to his height. He can't really play that. That's not appropriate for him. Just things that haven't been adapted for him.... I'd like to see more adaptive things for Andy. I'd like to see them doing, focusing around working with him and his disability.

In some instances, not fitting into the activity because of lack of adaptations resulted in exclusion from physical education. Helen, mother of 9-year-old Lisa, wanted Lisa more involved in activities with her classmates. She did not want to see a separate or special program for her daughter. Helen recollected:

I'd like them...to find more activities that she could be involved in. I don't know that she needs her own. If she can't play like basketball, floor hockey, she went to the OT room (occupation therapy). But I think modification is a huge thing. There's got to be the way you can modify things that she can do it. I would like to see that they can find some modifications and areas where Lisa can participate a little more.

Not all of the mothers' perceptions of curriculum adaptation were negative. Jeanette relayed how activities were modified for her son John (age 15). When the teacher felt the activity expectations were beyond John's abilities, he received an individual exercise program implemented by his TA who had been trained at the hospital. Although the completion of the exercise therapy program removed John from the activities of his classmates, his mother was pleased that he had the support of an instructional assistant during these times, even though he typically did not attend physical education. Jeanette recalled:

When the children ran around the gym, he could walk around the gym or wheel around gym. When they walked a balance beam, the teacher just put a masking tape on the floor for him to try walking along the tape. When the children climbed or kicked anything, he couldn't do that all. He just can't. The teacher associate last year would actually do therapy with John. He came to the hospital and learned some therapy exercises. When the class was doing something he couldn't do very much then John would do special exercise with his TA. That was very good. I was very happy because if he can't do what the class is doing, he should be doing something.

Andrea, mother of 12-year-old Julie, remarked that some physical education activities for children who use wheelchairs will never be appropriate:

When they do track and field, sometimes they go outside and some of the events are on the grass so shot put, she's very good at it. High jump, she'll never be able to do. Some are not appropriate because physically she's not capable of doing that no matter how many adaptations we made for it.

The mothers felt that some teachers seemed to have a little knowledge of spina bifida and its impact on their children's participation in physical education. Both the classroom teachers and physical education specialists were perceived to be lacking in their knowledge and understanding of the disability. According to a statement made by

Andrea, mother of Julie, (age 12) a lack of disability awareness contributed to her daughter feeling frustrated and being excluded. Andrea recognized the teacher was not deliberate excluding her daughter, but rather her lack of knowledge was a barrier to a more positive physical education experience for Julie:

Her [Julie] physical education experience was the teacher making her wheel around the gym. By the time she was done doing that, because she was required to do it three times, like every other child, she was exhausted and frustrated. She had usually missed most of the class instruction that took place once they're done their warm-up because the teacher didn't have an understanding of what her limitations were, or helping her to build her strengths and her skills. She didn't have an idea how Julie fits into the physical education program so she didn't treat it like it was important....Sometimes there is exclusion because teachers haven't put enough full thought or thought ahead about activity. I don't think the intent is to leave the child out but I think sometimes just that's an error of omission.

Erin, mother of 8-year-old Rebecca, also felt that her daughter did not receive the full attention that was needed. Although the reason for this is not clear, it may have been due to uncertain movement expectations resulting from lack of disability awareness. Erin recalled:

We had one year when things were really difficult in school. I felt like she was always the last to be considered. She [physical education teacher] wasn't a good match for her. I don't think she ever considered her, wanted her to be a part of class, you know. It was always everyone lined up and "Rebecca, you follow behind." that kind of attitude.

The mothers discussed the role of teaching assistants and their influence on their children's participation in physical education. Teaching assistants often followed the students from year to year, bringing continuity to the support they provided. It is often the teaching assistant who is credited with understanding the students' needs and abilities the most. Andrea, mother of Julie (age 12) explained:

I think a TA is necessary. She has a really good understanding Julie's disability, what her limitations are, what her capability is. For this particular circumstance, having a TA is very valuable because she has the time to pay attention to things that her teacher might not.

The mothers' messages about teacher assistant support were contradictory, but upon closer reflection it became clear that the perceived need for teaching assistant support was context and age specific. In activities that required high levels of expertise (sit skiing) or demanded enhanced supervision (skiing), the support of teacher assistants was perceived to be important to success. In contrast, however, as the children became older, the social and instructional appropriateness of a constant adult companion was questioned.

Margie, Dustin's (age 14) mother relayed an instance when special arrangements had been made to provide an instructor (teaching assistant) with a background in sit skiing to support his participation on the hill. Even with this support, Margie was disappointed with Dustin's level of engagement in the activity.

When the class went skiing, he was going to be trying out the sit-skiing, you know, a special apparatus for handicapped kids and I just happened to go with the school because I drove the school bus out there. I wanted to watch him.... A whole morning he sat inside and drank hot chocolate. I said "why weren't you skiing?" "My instructor is busy. He's teaching the other kids." That instructor was supposed to be for him alone....He [Dustin] went down hill three times in the whole day. That really upset me.

Although Margie expressed the need for teacher assistant support for her son for an activity such as skiing, she recognized the dependency that can be created when a teaching assistant is overly supportive or is with one child for too long. Margie intervened on the nature of her son's teacher assistant support.

I was getting worried in elementary school. He had the same lady right from kindergarten to grade 6. She was like his mother, almost like she did everything for him. I had to keep telling her. I think Dustin got so used to her. She did everything for him and that's not good, so I switched to a male in Grade 7 and that was a lot better....I think he is grown up so he doesn't need it [TA's support]. I think he's capable of doing and working on his own.

Bonnie, mother of 9-year-old Andy, concurred:

It's really good. She's been advocated for him. She [Andy's TA] would be a person showing him how to do it and encouraging him to do it. She's just very aware of what he needs. In this particular school year, the TA is there [physical education class] but is moving herself more and more from him. He learns independence and learns more that he can do things on his own.

Swimming was a context that created challenges for participation due to teacher assistants not having the skill set required to support the students in the pool. In some instances, mothers had to stand in as teacher assistants which created concerns about the social ramifications. Erin, mother of 8-year-old Rebecca, recalled a swimming experience:

...for swimming, I'd like her to be within an adult arms reach sort of thing. When her school goes swimming, her TA actually doesn't swim. My husband and I go with her, but I feel like she's starting to notice her mom is the only one with her in class.

Jeanette, mother of 15-year-old John, also remarked: "We just need somebody with him. The school goes swimming but his TA never went in the water. It was hard."

4.2 Connection to Disability Sports

The mothers felt that participation in school physical education established a positive attitude toward physical activity. Since they found that there were limits to their children's participation in physical education, they also wanted their children to be involved in disability sports. Thus, these families joined physical activity programs provided by Saskatchewan Wheelchair Sports Association, Spina Bifida Association, and Kids... in Motion Dance (i.e., family wheelchair sports camp, swimming, and wheelchair dance). Learning skills related to disability sports while in the community context also was perceived to have benefit to their children's participation in school physical education.

4.2.1 Enhanced School Participation

The mothers felt that physical activity experiences outside of school inspired their children to engage in school physical education with more confidence as they became more secure in their ability to participate. Andrea, mother of 12-year-old Julie, explained that wheelchair basketball helped Julie to be more active in physical education:

She was involved with that [wheelchair basketball] for couple of years. Having this couple of years of experience has really helped her in her physical education at school because she already knew the rules of the wheelchair basketball. When they started learning basketball in the physical education class at school, she was able to tell the teacher about the rules. They had a wheelchair there so that they have someone participating with her, and she was very confident and very involved in the physical education class.

Another skill Julie developed through disability sport was sit-skiing which enabled her to participate in cross country skiing with her peers without disabilities:

We started out with sit-ski. She did sit-ski with a group of kids who were in wheelchairs. It's a more even playing field for her. She's at the point where she developed enough skill level to ski with other children who had disabilities. She now participates with her class so a sort of reversing it. She developed first her skill level in a group of children with disabilities and now she's moved onto skiing with her peers, able-bodied kids.

Erin, mother of 8-year-old Rebecca, stated that Rebecca had been involved in disability sports since she was five years old as it provided a context where she could be in contact with others of similar ability and come to understand how her body moved and what her strengths were. The experience obtained from disability sports in turn helped Rebecca to participate in school physical education:

The activities that she does outside of school are segregated. It is a level playing field and I think that they need to have a place for segregation because I think the competence she's built from doing that. It gave her some sense of competence to do the activities I think. In the school, she is the only one in a wheelchair so I think she needs to figure out how she is going to be involved and be successful. I think it helped her to figure out how she's going to participate in physical education.

Kim, grandmother of 14-year-old Megan, encouraged Megan to participate in disability sports programs. It was there she developed her social skills. The outcome was a positive influence on Megan's participation in physical education. Kim became Megan's full-time caregiver when Megan was 9 years old. Kim found that Megan did not have friends and did not actively participate in school physical education programs:

When she was younger, she was sitting on the ground and doing nothing. I walked by the school and she was sitting in the corner. When I got her, she didn't have friends coming over. She wasn't known to be a talker so I just thought she can't go through life this way. She's got to meet people and that's why I got her into the sports [disability sports] because then she gets to meet the people...She gets to know people and have fun with them.

Kim provided photos of Megan's sports participation, highlighting her pride in her participation (see Photos 4.4, 4.5, and 4.6). Kim wanted Megan to participate in school physical education actively and she believed experiences in disability sport would influence her participation in physical education: "She loves it [physical education] now. She gets out there to join in and do whatever, whatever it is just to be with the kids and she doesn't hesitate to participate in it."



Figure 4.4 Megan (left) cross-country sit-skiing



Figure 4.5 Megan (far left) with her wheelchair track team



Figure 4.6 Megan in swimming

According to the stories of Margie, Dustin's (age 14) mother, and Jeannette, John's (age 15) mother, the experience of participation in various disability sports (e.g., wheelchair basketball, wheelchair racing and sit-skiing) for these high school aged participants was similar. Involvement in disability sports provided motivation for their children to be involved in school based physical activities. Margie said, "...in high school now he joins the wrestling team." Jeanette explained:

I anticipate that the high school should be able to let him do as much in physical education program as he can. They let him be on the track team.... It's very important in high school to be a part of that.

All of the participants wanted their children to be included in as many activities with their peers without disabilities as possible and they believed the experience of disability sports facilitated their participation in school physical education.

4.2.2 Developing Disability Sports Skills

Along with school physical education, the experiences of participation in community physical activities were also discussed by the mothers even though these experiences were not requested through the interview process. Participation in regular school physical education was also an impetus for their children to be physically active outside of school. The mothers felt that it helped their children to participate in community physical activities as well as it improved their fitness and interest in being active. Andrea, mother of 12 year old Julie, stated:

It [physical education] has played a big role in her ability to stay at her school and in her ability to participate in her physical activities outside of school. If she had no physical activity at school, her dancing would be harder and her swimming would be harder.

Bonnie, mother of 9-year-old Andy, added, “It [physical education] helps the kids get rid of a little steam: encourages them to be physically active outside of school.” Helen, mother of 9-year-old Lisa, said, “I think she needs it [physical education], she needs exercise because I mean it keeps her active.”

The mothers encouraged their children to be involved in community based physical activities for reasons of skill development which had concomitant self-confidence benefits. The link between school physical education and disability sports participation were reflected in Helen’s recall of her daughter Lisa’s (age 9) PPP meeting. It reflected depth of understanding by the school and parents of the benefits of aquatics. On Lisa’s progress report it stated, “Lisa increased her confidence and enjoyment in the water... supporting the limbs and limiting the impact on the joints...it would be beneficial and fun for her to swim more regularly.” Following the PPP meeting, Helen enrolled Lisa in community swimming and wheelchair dance program.

Andrea, mother of 12-year-old Julie, felt that there was a difference in the skill level of Julie and her peers without disabilities. Julie’s skills were often behind that of her peers without disabilities. Andrea encouraged Julie to participate in physical activities outside of school because of their many benefits that were not necessarily achievable in school physical education:

She [Julie] was in a horse back riding regularly...in terms of her balance it made a huge difference for her ability to use her wheelchair. Dancing has been really good for her self-esteem. It’s almost like a social activity to some degree because they performed in the community and I think it helps to increase awareness about what someone in a wheelchair can do. It’s healthy for her aerobic and cardiovascular health. Swimming has been so good for her because of her strength and self-esteem. She used to be very afraid of swimming and now she has so much more confidence and again it increases her self-confidence because she is doing what every other child does.

Andrea also felt that Julie was developing more self-confidence by participating in disability sports:

She would participate in the wheelchair basketball sessions that they had in the City Hospital. In a few short sessions, just being around other people who are in wheelchairs, she started to have dramatic changes in her own self-perception and her own idea of what she could be or accomplish. She kept saying that I can do it now.

Jeanette, mother of 15-year-old John, felt there was a place for wheelchair sport, particularly when students reach secondary school age. She wanted John to have the same experience as other children but recognized that a high level of play for John could occur within the setting of wheelchair sports:

When he got bigger, he couldn't compete in the basketball and soccer. He did all those when he was really small. But you know there is a point and certain sports where people who can't run, just can't participate.... They have to go on to at a special level, by grade 8, ...Certain things have to go into the wheelchair side of things so then he's equal with his peers in that sports.

4.3 Beyond the Curriculum

Although the mothers were actively involved in their children's educational programs, their involvement with the school was often focused on increasing other's understanding of spina bifida. They communicated with the school on a regular basis and provided disability awareness information and sessions to teachers and students, made arrangements for the use of adapted equipment, and arranged demonstrations of disability sports. They were also involved in the PPP progress and used this opportunity to share information about their children and their potential.

4.3.1 Bringing a Different Frame of Reference

The mothers indicated that one of the most important reasons for their participation in the schools was to help teachers, instructional assistants, classmates, and others to see their children as the same as other children with respect to abilities, desires, and motivation to be part of the larger group. They recognized it was important for people to understand the meaning of the wheelchair and why their children used them but also that they were more similar to the other children than they were dissimilar. The mothers participated in two forms of disability awareness in the schools. The first related to disability awareness or more specifically, information about spina bifida and its impact of movement and mobility. The second was disability sport awareness that included information and practical sessions on sports participation using wheelchairs. These sessions were in some instances lead by the parents. Alternately, the parents were instrumental in bringing others into the school.

Helen, mother of 9-year-old Lisa and Lisa's physical therapist prepared and delivered a disability awareness session for Lisa's classmates (see Figures 4.7 and 4.8):

We set up the meeting for her to explain some of her situation to her class. We brought a physical therapist from the Kinsmen center, came out and tried to explain in children terms. They brought out Petti [a doll], she's got spina bifida as well and is in a little wheelchair. They basically tried to explain to her classmates why she's in a wheelchair and what it means to her, you know. It was a good session because it seems they understand a little bit better why Lisa is in a wheelchair.



Figure 4.7 Lisa, physical therapist presenting disability awareness session to Lisa's class



Figure 4.8 Lisa participating in disability awareness session

The Saskatchewan Wheelchair Sports Association was instrumental in bringing wheelchair sports demonstrations (e.g., wheelchair basketball, wheelchair rugby) to the schools. As well as providing information on wheelchair sports, the students are given an opportunity to use wheelchairs and participate in basketball drills and games. Helen, Lisa's mother, recalled:

The Wheelchair Sport Association came out one day. Different classes got their turn. They brought out a bunch of wheelchairs and so other kids were kind of getting a chance to sit in the wheelchair and play basketball and different things. That was a kind of neat.

Andrea, mother of 12-year-old Julie, spoke of Nick who used a wheelchair because of his spinal cord injury while visiting Julie's physical education class and presented information on spina bifida and disability sports. Nick also gave the students an opportunity to experience physical activity in a wheelchair. The outcome of the information session within the context of physical education had far reaching results. Other students came to understand the day-to-day challenges faced by someone who uses a wheelchair. Andrea explained the enhanced understanding, empathy, support for self-reliance, and the advocacy benefits resulted from a member of the disability community leading wheelchair sports awareness sessions in physical education classes.

Andrea explained:

Nick did a wheelchair awareness session with her class and worked with teachers on how to adapt different games and activities. He talked about adapting activities, safety and acquiring a disability.... He brought in a whole bunch of different wheelchairs and then all of her class got to try wheelchairs and see what it is like to do physical activity in a wheelchair which was really big for Julie's self-esteem and big for the kids because putting them in the wheelchairs gives them an experience that they can think about, 'if I had to do this from the wheelchair, how would I do it instead of you can't do that because you're in a wheelchair?' So it gives a different mind frame. They had a better understanding

of some of Julie's struggles. It serves a double purpose to gain more empathy in some areas, and accessibility was big one. 'Well you can't get through that door what's wrong with this' you know and then the students will go to the principal saying 'you have to fix that.' On the other hand, when it was a situation that she could have easily coped with herself but was choosing not to then made to call her and say 'come on you can do it if you want to' So it was interesting that the purpose for doing the wheelchair awareness was to create more empathy and a bigger understanding or better understanding. I would say that Nick's involvement in Julie's physical education experience has really helped the kids have different perception of Julie because seeing an adult who has all these skills and abilities in a wheelchair, produces a lot of admiration, you know. It gives them a different look and different view of the person.

As some of the children were members of the Kids...*in motion* wheelchair dance team, the dancer troupe performed at the dancers' schools. Bonnie, in particular highlighted her son's involvement in the dance program to his teacher and teaching assistant during a PPP meeting. Subsequently, a dance performance was held at the school (see Figures 4.9 and 4.10). Bonnie felt the session was very valuable for the children as it provided an opportunity to better understand Andy's ability and wheelchair dance. Bonnie recalled:

I'd like to see more stuff brought into the school so maybe Andy could suggest.... He has done this before. He brought in a group [wheelchair dance team] then showed some of stuff that they can do and I'd like to see that kind of stuff brought into the school so that more awareness what's out there for children with disabilities, not all the time, but sporadically, so that kids are more aware of. I think that's important that there's more awareness out there.



Figure 4.9 Kids...*in motion* wheelchair dance team demonstration



Figure 4.10 More wheelchair dance

4.3.2 Keeping the Balance

The mothers perceived it was important to them to share information relating to their children with school personnel. They described two types of communication methods used to support their children's success in school; the PPP process and personal communication. The PPP process was a structured time where mothers could discuss their children's educational programs with school personnel. They also had occasion to talk with classroom teachers, teacher associates, and resource teachers individually, on an ongoing basis.

The mothers perceived the PPP as a very important tool through which they could be involved in their children's education programs planning. The PPP process was to identify children's strengths and interests and to look for ways to assist the children's learning. The mothers could see the goals and objectives of programs and their children's progress. They were also able to discuss their children's programs with numerous school personnel. Bonnie, mother of 9-year-old Andy, explained:

It [PPP] starts with the areas of strengths for him and then it goes to areas in need for development and ways to support learning. We discuss his academics, how he's doing with friends, and we set up goals for him....It tells who is involved with him in learning and the special equipment that he uses. The other support is his speech-language pathology and personal consultant.

The PPP process in the level of elementary school on occasion involved a multidisciplinary team depending upon the particular needs of the student (e.g., physical therapist, speech therapist). Helen, mother of 9-year-old Lisa, also explained that the PPP team presented their knowledge and ideas in developing a program guideline for Lisa and that she had an opportunity for input into the goals set out for the year. Concern

was expressed, however, at the lack of attention given to physical education in the PPP process and how the motor development component was interpreted to mean physical management (e.g., lifting and therapy exercises).

We discuss who her teacher is going to be and TA is going to be. We discuss things like what her needs are going to be for her next year, what is going to be her focus, what we want to focus for her, or how we are going to focus on for the next year...so we sit down and discussed it. They'll tell me where they'd like to see her go and I'll say this is where I'd like to see her go....Mrs. K [physical therapist], she comes out, I think usually once a week. She has explained lifting and the exercises that they can do for her every time....She's [physical therapist] not the physical education teacher but planned her program, the physical part of it. We've never really planned physical education other than mentioned the importance of walking.

Andrea, mother of 12-year-old Julie, also indicated that the PPP was a valuable tool for developing the program guidelines for Julie's learning but concurred that physical education received little attention and participation would become a greater challenge in subsequent years with the shift in curriculum focus. She explained:

I think it's effective for identifying gaps and problems and for being able to sit down and discuss what the solutions are... I would say that there is not a lot of focus on the physical education, but she participated in the leisure and recreation activities in school and out of school so some of goals were to participate in swimming, dancing and skiing. Probably we will see a big shift in next year for her physical education because once grade 7 it's far more competition-based than skill-based....Strategies and resources which we did were getting the proper equipment for cross country skiing in school and also anticipating ahead of time what she will need to participate in non-routine class activities or activities away from the school. Sometimes it's an issue. If the class takes a trip, there's no accessibility. They've done bowling where they haven't had accessible bowling area.

The mothers of high school aged children expressed less concerns with their role in the PPP process. They also appeared to recognize that the high school structure was one that encouraged, and indeed, required, more independence on the part of the children. In

essence, the role of the PPP process changed. The mothers of the older children used additional communication methods for staying in touch with school personnel and the educational progress of their children.

The mothers also felt that the members of the PPP team were willing to receive parents' concerns and requests and to facilitate mothers' suggestions about the programs. Bonnie, mother of 9-year-old Andy, expressed the satisfaction of the PPP meeting in which she was involved: "I really find it very good. I look forward to that because it's a time we can all sit down and really say what needs to be said and find out what's needed for him." Erin, mother of 8-year-old Rebecca, thought that the members of PPP team contributed to the development of Rebecca's programs and she felt her concerns were treated seriously. She also highlighted its importance in communicating information from the parents' perspective. Erin stated:

It [PPP] is the only real formal method of communication between home and school. They [PPP members] are approachable. They're very positive. I mean people there [PPP meeting] really concentrate on the strengths, things like that. That's really good. We always know that there is a room for growth and room for improvement. I think they are open to suggestions. I think everything I say gets written down. I feel like they do take what I say seriously. I really feel like this year has truly been a team approach.

Helen, mother of 9-year-old Lisa, also felt that she received the full attention from the members of the PPP team:

They [PPP members] are really good. They tried to take our feelings, our thoughts, you know, suggestions into consideration when they are planning. I'm lucky. If I do bring up I want her more physically involved they would do it and they would find a way to do it....It [PPP meeting] is really good. Everyone's willing to go there. All want to be a part of it. Everyone's like I said eager to attend there so we have to really set up a time when everyone can go.

Andrea, mother of 12-year-old Julie, indicated that she perceived her role to be that of guiding the members of the PPP towards understanding who her daughter was, both in and out of school. She highlighted the need for sincere participation on the part of the parents if the PPP process was to be meaningful. She took it upon herself to make things happen for her daughter by assisting with curriculum adaptations. Andrea explained:

I would say it's a guidance role....We always talked about the physical activity, extra curriculum, what she's involved in. We talked about goals, like our goals for Julie what we've seen for her....I wouldn't say like an observer but when the program in the curriculum is already in place, we have to accommodate and adapt the curriculum. Sometimes I think Julie's abilities and skills are not recognized because some of her skills are outside of the room of the curriculum. I mean I definitely tried as much as I can take an active role....We put a lot of time and energy into discussing and coming up with the solutions. There is always a role for us to play at home. If we do have a PPP, we always have our job to do so I feel that we've done all this work to develop a good tool for us to use it for the year of her. If people in that process are not taking their role and not doing their responsibility, it completely defeats the purpose of the PPP....If we look at the PPP, we will come up with the plan and the way of handling or dealing with situation. Very often unless it's initiated by the parents, it doesn't happen. The skiing is the one so far at the school.... If you really want something for your child as a parent, you have to be the one to initiate.

Margie, mother of 14-year-old Dustin, also emphasized the necessity of parents being involved in the PPP process. She indicated that the PPP could be an efficient tool for facilitating their children's learning if the parents were actively involved in the process and see it as a shared responsibility between family and teaching staff. Margie explained:

I think it's important if you make it important. Like some parents might just go and do it. But if you don't know how to apply it, there's no point even having it. You have to read and bring your paper home to see what his goals are and what they've set up for him. If he can't reach those goals, you have to try to help him to reach those goals. In the end of year when we have the program, you should be able to say, as a parent, "Yes, he can do or No this wasn't met. Maybe try something for next year.".... It works both ways. If they see the parents were

interested in the child, and then they're going to make an effort as well and keep you child involved. I think we both have to work at it. It's not something that is easy for either teachers or parents.

Even though the mothers were generally satisfied with the PPP process, some mothers expressed "frustration" when expectation changed from year to year as school personnel interpreted the PPP process differently. Mothers' frustration surfaced when they perceived the PPP was regarded as paper work that had to be completed and did not translate into the implementation of specific educational goals or objectives. Andrea, mother of 12-year-old Julie, recalled:

I don't know if it depends on the teacher or if it's just the system as a whole. But I find that some teachers treat the PPP as a nuisance. It's something that they have to do so they do it. I feel that as a parent, I put a lot of energy into trying to explain to them where Julie is at, where the family is at, what our goals and expectations are. If I feel that the teacher isn't taking that seriously or they are just doing that because they have to, I feel like, 'what's the point', it's not going to go beyond this. I mean it's on the paper, but if it doesn't go from the paper to the practice then you get really frustrated.... it can make life more complicated for Julie at school so we have to try to keep the balance.

Helen, mother of 9-year-old Lisa, expressed her frustration as follows:

The year before I thought I had made myself very clear and at the end of year I stressed, this is who and what I want her to have, and this is why. I felt they ignored me so I got hold of the school counselor, and I stressed my concerns. We set up the meeting.

The membership of the PPP team at the high school level was not selected from a multidisciplinary perspective. The members of the PPP team consisted of parents, the special education teacher, and the TA. Jeanette, mother of 15-year-old John, stated that the members of the PPP team have decreased in John's high school: "It was just me, the resource room teacher, and TA, but in elementary, the principal came and classroom

teacher.” Margie, mother of 14-year-old Dustin, stated that the PPP process was not utilized as extensively in planning Dustin’s educational program as they did in elementary school. She felt this was appropriate as it increased his self-accountability although it decreased structured opportunities for the parents to meet with school personnel:

In elementary Dustin was followed more closely but I think that’s only proper because he’s younger too. But in high school they expect him to do lots more on his own because he’s growing up now and he’s got to be more responsible. So they put that on his own a lot more than in elementary school. We had more meetings [elementary] than high school.

The second form of communication described by the mothers was personal communication. They took advantage of a teacher-parent interview sessions with the classroom teacher. They also utilized informal contact through the telephone, email, and communication booklets with classroom teachers and TAs. They also felt they were welcome to drop by the school and meet individually with teachers and others as needed. The mothers actively pursued these forms of communication.

Erin, mother of 8-year-old Rebecca, said that she could talk to the physical education specialist if she had ideas for programs or concerns for Rebecca. “Rebecca’s physical education teacher is very approachable. I wouldn’t hesitate. If I had a concern or something, I would just ask her for a minute or raise concerns.” Bonnie, mother of 9-year-old Andy, also recalled that she was welcomed to school:

At any time I can go into the class to ask the teacher about the program or go to the TA. I actually come to the school every Thursday. I mean I can ask at any time Andy’s teacher, “How he’s doing?” It’s very open and it’s very informal.

Margie, mother of 14-year-old Dustin, indicated that she could access Dustin's program and progress via the internet. The teacher was also proactive in soliciting ideas from mothers about upcoming units via the telephone.

One of his teachers give me the web address and I can actually go on there and check his marks and even see how he did that day. That's a good tool. If he feels he wants to talk to me or Dustin's getting behind, he just calls me. The teacher would ask me 'We're going to be doing this. What should we do with him and how can he be helped?'

Some mothers felt that the teacher-parent interview sessions were too short and they should be given more time consideration given the needs of their children exceeded that of their children's classmates. Andrea, mother of 12-year-old Julie, stated:

We do have teacher interviews but I find it equally as frustrating because you only get minutes to fit in with all these other children, you only get minutes to talk about the whole, her whole education for the year. You might focus on one thing or the teacher might be focused on one thing. That means not what you want to talk about so I find it's not sufficient. If the educational system wants parents to play a stronger role in the education of children, I think the parents need to be given a stronger line of communication at the school.

Due to the brevity of teacher-parent interviews and the limited flexibility of teachers to meet, the mothers communicated more frequently with the TA than the teachers. Communication with the TAs was frequent and welcomed. Andrea, mother of 12-year-old Julie, relayed:

I'm very happy with my communication with the TA because she is continually updating me on what Julie's progress is. She continually is encouraging. She'll point out the problems without being a negative thing about her. She is very good at working with us and very good at trying to make things happen. She has been very good at making sure that the adaptation is taking place as much as possible. If we see a gap somewhere and something needs to take place in it, she is very good at getting things worked out. If there are any concerns about her in a physical activity, she will tell the teacher or she'll contact me.

Bonnie, mother of 9-year-old Andy, said there was no limitation in communication with the TA: “It’s always very good, very open. She’s available at any time. During the day she can phone me at home. If she sees me at school, she just tells me there’s a problem whatever.” The individual nature of the relationship between parents and school personnel was highlighted by Jeanette, mother of 15-year-old John. She felt better about the communication she had with John’s high school TA than his elementary school TA. She felt that the TA was very supportive: “It’s so much better [at high school]. He phoned me. It’s wonderful. The TA is very good in high school. The most important thing was that he reads all the information [spina bifida and disability sports involvement] that I gave him.” In high school, she could also discuss John’s programs and his participation with his teachers and TA at any time and received prompt feedback from them.

Erin, mother of 8-year-old Rebecca, used a booklet to communicate with Rebecca’s teachers and TA when she was in early elementary school. She recorded notes about how Rebecca was feeling and her needs of the day: “We have a little booklet they sent back and forth....it worked really well in that earlier grade. This year it’s been used very minimally. I’m still keeping it her backpack in case I want to try mention anything.” In a similar way, Kim, grandmother of 14-year-old Megan and Helen, mother of 9-year-old Lisa, also kept a daily communication book to exchange information with the TA. Helen illustrated Lisa’s day at home and her TA depicted her school day in the communication book. Helen recalled: “I actually keep fairly good contact with her [TA]. We keep a daily communication log. Everyday we write. There is a little something in there. They tell me what they did. We do have very good communication.”

The experiences of parental involvement in their children's educational process were very active. They tried to include possible ways that they could support their children's participation in school programs. They also believed that they should participate in the program planning and then their children's learning could be successfully achieved. The parents actively communicated with school personnel throughout the year. They attended scheduled PPP meetings and teacher-parent interviews. They also established other forms of communication that kept them in touch with their children's education goals and progress toward them. In all cases they felt their active involvement in program planning and reporting was a role they must play and they felt their input was appreciated in the partnership between home and school.

5. DISCUSSION

This phenomenological qualitative study was to gain an understanding of the parents' perceptions of their children's experiences in inclusive physical education. The stories of 4 mothers of elementary school children (1 boy and 3 girls) and 2 mothers and 1 grandmother of high school children (2 boys and 1 girl) were gathered. The findings of this research portrayed mothers' values of physical education and described their roles in the involvement in the educational process for their children with disabilities thereby adding their voice to the ongoing dialogue surrounding inclusive education. Peters' (1996) model of disablement provides a constructive guide for the interpretation of the findings of this study. This framework is an integration of perspectives (i.e., insider, outsider, and interventionist) on disablement, the contexts within which disablement occurs, and interaction among these perspectives and contexts.

The first emergent theme, *a good thing but...* reflected physical education as perceived subjectively through the eyes of the mothers or grandmother as being support of the social and physical development of their children, but at the same time there were barriers to participation associated with environmental shortcomings. The interaction of the person with the environment was not always positive. In addition, the way that the curriculum was to be taught, interpreted, and delivered reinforces the differences that

had social implications for the self-esteem and self-confidence of the children with spina bifida. Teachers' lack of understanding of disability brought about the restricted participation of the children with spina bifida within the context of physical education. That is, the interventionist perspective of the teacher and the interpretation of the learning activities had the potential to accentuate the disablement process.

The mothers of this study concurred with previous studies that inclusive physical education contributed to the health and social skill development of children with disabilities (Block, 2000; Suomi et al., 2003; Downing & Rebollo, 1999). Physical education was recognized by the parents as an intervention to maintain a healthy body weight and to prevent obesity through engagement in a physically active lifestyle. Children with spina bifida use a wheelchair for their mobility so they are less physically active than their peers without disabilities. Social, physical, and environmental barriers decrease opportunities for spontaneous exercise as experienced by their peers without disabilities. The mothers believed that school physical education was valuable for teaching knowledge about a healthy lifestyle but also helped them experience the means by which to maintain a healthy body.

The mothers also viewed physical education as beneficial to the development of social skills including friendship, enjoyment, sense of belonging, and self-confidence. This finding supports the work of previous research (Erwin & Soodak, 1995; Ryndak et al., 1995; Wilson, 1999). Some mothers believed that the "friendship" and "enjoyment" were more important outcomes than the health benefits (Wilson, 1999; Hamre-Nietupski, et al., 1992). The process of making and retaining friendships that appears to come automatically to most children is not always the case for children with disabilities

(Goodwin & Watkinson, 2000). The mothers in this study wanted their children to be able to enjoy their time with friends both within and outside of the school setting. Also, physical education was recognized as a context for their children to increase physical and social interaction with their peers without disabilities.

The sense of belonging described by the mothers as a social benefit of inclusive physical education has been previously reported (Goodwin & Watkinson, 2000). The mothers represented it as ‘being included’ and ‘being a part of group’. The physical education program was not just participating in physical activities, but having an active role in the activities as well. The parents perceived that the participation in physical activities with the peers without disabilities helped their children to feel acceptance and diminish the “difference hurdle” their wheelchairs represented. Physical education programs were important in increasing self-confidence and self-esteem of the children of the mothers interviewed, as has been previously reported (Shapiro et al., 2002). The mothers of this study observed the disadvantage their children were at socially and physically. Peters (1996) refers to this as the outside perspective or disablement as observed. The children’s mobility impairment had direct implications on their involvement in physical activity, which if left to run an uninterrupted path could lead to health concerns and secondary impairments that could lead to further loss of function.

The potential for social isolation, lack of belonging, and negative self-esteem that can result from having a disability was also acutely evident to the mothers. Without intervention, the social ramifications of their children’s disabilities could also further impair their cognitive self-appraisals. The mothers were cognizant of the impact that their children’s disabilities could have on their children’s quality of life in the short and

long term. Physical education and community sports participation were acknowledged as important in maintaining physical and social health and arresting the advancement of the disablement process.

The benefits associated with physical education also were marred by environmental limitations placed on participation. The “participation barriers” of safety, environment, and instruction add to previously reported literature of barriers to participation that have been expressed by students and teachers (Blinde & McCallister, 1998; Block, 1999; Goodwin & Watkinson, 2000; Lieberman et al., 2002).

Mothers expressed concern over the safety of their children during participation in physical education program. Students with disabilities may not have the same level of speed, strength, balance, or coordination as their peers without disabilities. Such divergences can lead to injuries. The present study revealed that issues of safety arose due to facility, program activities, or disability awareness shortcomings. The mothers felt that participation in physical education could place their children in harms ways on occasion. More specifically, the parents described the class size and the size of gymnasias as potentially contributing to unsafe environments. This finding was previously reported by Downing & Rebollow (1999).

Environmental barriers included ‘equipment’ and ‘wheelchair accessibility’. Physical education at times required the use of special equipment that is not readily available or affordable to families of children with disabilities. When classes went biking, for example, the mothers needed to locate a hand-crank cycle if their children were to participate in this activity. The mothers actively assumed the interventionist role outlined in Peters (1996) model of disablement. The mothers in many instances sought

concrete ways to support their children in overcoming the limits to participation in physical education that arose due to their mobility impairments. The role of interventionist is often associated with rehabilitation practitioners, teachers, or instructional assistant within the educational context. These school based personnel intervene to maximize the students' abilities by providing educational supports. The experiences of the mothers in this inquiry suggest that they too play a significant interventionist role by translating their knowledge of their children's abilities into active participation. This was done on numerous levels including the mothers providing instrumental support by locating sports equipment to enhance participation. The mothers most able to do this were those who had their children involved in community based disability sport and hence possessed the requisite knowledge. If the mothers did not have this knowledge or take the initiative to provide equipment support, their children were at risk of being excluded from active participation. The mothers also spoke of the need for the modification of standard equipment (e.g., shorter hockey stick, lower basketball hoop), the absence of which could also limit their children's participation in physical education (Lieberman et al., 2002).

Wheelchair accessibility of facilities had the potential to exclude children who use wheelchairs from some physical education activities. This is not a new discovery, although this has not been reported previously by parents (Doubt & McColl, 2003; Goodwin & Watkinson, 2000). Mothers observed the restrictive nature of physical environments (e.g., access to weight room, grass) on their children's participation in physical education. Their influence or ability to intervene in regards to this participation

barrier was limited and required action from policy makers as new schools are built or existing schools are refurbished.

The last obstacle to their children's participation in physical education related to the implementation of the program. The mothers spoke of limited curriculum adaptations and knowledge of disability. Similar barriers have been reported for students with visual impairments (Lieberman et al., 2002). The mothers in this study felt that the adaptations were not always implemented although previous studies have reported the importance of curriculum adaptation and modification to achieve success in inclusive physical education (Block, 2000, 1994).

In addition, the mothers felt that the teachers' lack of knowledge of spina bifida and its impact on movement often produced barriers to participation in physical education. The mothers provided disability awareness sessions to the staff and students of the school, as will be discussed later. This effort to intervene on the part of the mothers so as to enhance their children's educational experience was often not sufficient in scope and depth to address or anticipate the need for curriculum adaptation. Mothers became particularly frustrated when their efforts to inform school personnel about spina bifida through written material were not read. Although this information may not be recognized as directly relevant to the educational context it provides the objective view of spina bifida, or what Peters (1996) calls the outsider perspective needed to link the child with spina bifida to the physical and social environments found in schools. Information on the impact of paralysis on circulation, bone strength, skin care, balance, strength, and physical sensation are all of direct relevance to participation in physical education. The importance of relaying this information is often left to the mothers and

their frustration of not having it heard or read was expressed. The need to establish links between disability observed (e.g., teachers and instructional assistants), disability intervened upon (e.g., parents), and disability experienced (e.g., students) becomes very apparent. The need for open, respectful, and ongoing communication would appear to be fundamental to a positive educational experience for teachers, parents and students alike.

The second emergent theme, *connection to disability sports*, linked the children's involvement with disability sport in the community with their participation in physical education. Disability sport was valued by the mothers as it was the intersection of the insider and outsider perspective of disablement (Peters, 1996). The mothers worked to integrate their understanding of their children's subjective experience of disability with their objective knowledge of spina bifida and bring them together in the context of disability sport. The text book definition of impairment becomes invalid within the disability sport context as this environment equalizes function among all participants and in essence removes the social comparison that fundamentally constructs the notion of disability (DePauw & Doll-Tepper, 2000).

The present study revealed that the experiences of disability sports were also supportive of participation in school physical education programs. Mothers explained that participation in disability sports provided valuable skill development that transferred to the goals and learning objectives of physical education (Sherrill, 1998). Disability sports also were perceived to influence the physical fitness and self-esteem of children with physical disabilities (e.g., wheelchair sports, swimming, skiing). Being with a group of people who have disabilities increased the children's understanding of their

bodies, how they moved, and provided a social context in which to learn about their disability culture.

When we enlist the support of the *interventionist perspective of disablement* (Peters, 1996) to understand the importance of disability sport, we see the importance of involving peers without disabilities. The peers become active agents in breaking down social structures that can limit participation in physical education (e.g., low expectations, helping too much, dismissing potential). Mothers perceived disability sport demonstrations to be an efficient means of bringing the children together in a common experience that focused on ability and not deficit. The elementary school children who participated in wheelchair dance class regularly performed in public and on occasion would perform in their respective schools thereby broadening their peer's understanding and knowledge of disability and disability sports.

It is worthy of mention that the PPP of the children seldom addressed physical education. In fact, the form used in Saskatchewan uses the heading motor development (i.e., fine or gross) (see page 123). The terminology reflects an outsider perspective which is situated within a medical model, not an educational framework. It becomes clear why the importance of physical education may be overlooked by members of the PPP team. Mothers recognize the value of physical education, but it would take a tremendously informed mother to make the link between the goals and objectives of physical education and the PPP heading of motor development (i.e., fine or gross). The form used in Saskatchewan would appear to be reinforcing a medical model of disablement that encourages rehabilitation over a model that recognizes the interaction

of impairment or disability with the environmental, social, and cognitive parameters of the educational setting.

Beyond the curriculum, the last emergent theme in this investigation, presented the mothers' perceptions of their roles in the education process. The findings of this research reported that parental involvement was focused on increasing others' understanding of disability and illustrating the meaning of the wheelchair. The first subtheme, "bringing a different frame of reference" reflected their direct involvement, or what Peters (1996) terms intervention, in their children's education program by providing disability awareness sessions. The disability awareness sessions were important for the parents in that they wanted to share what their children could do, without ignoring the obvious differences observed (from an outsiders' perspective). Some of the mothers reinforced the positive management about ability by actively intervening and arranging for disability sport groups to come to the school and hold demonstration sessions. In this way they brought a different frame of reference to school personnel and students – one that promoted ability and down-played disability. Said differently (?), a "different frame of reference" speaks to the parents' involvement in helping others to see their children beyond the outsider deficit model/(dis)ability model and increase their receptivity to hearing and learning from the subjective experiences of their students, or what Peters (1996) refers to as the insider's perspective.

The mothers recognized that the preparation of teachers in teaching physical education to students with disabilities was in all likelihood minimal. This insightful observation has been reported previously (LaMaster et al., 1998; Lieberman et al., 2002; Suomi et al., 2003). In response, some mothers took the initiative to support the teachers,

and ultimately their children, by bringing knowledge of disability sport to the school. This was accomplished by arranging for in school disability sport demonstrations, locating and loaning special equipment (e.g., sit ski), and providing contact numbers for community programs, and volunteering to accompany classes on outings. The mothers took on an interventionist perspective (Peters, 1996) that was founded on the similarities between children with and without disabilities, and not their differences. These mothers recognized and used physical education to send this message.

It is clear that for an interventionist perspective to be welcomed in a school setting and not be seen as meddling or interfering with the educational process, a strong partnership between family and teaching staff is needed. Some literature has gone so far as to suggest that parents should have the option to waive their participation in the PPP process and leave all decision making to school professionals (Gerber et al., 1986). In light of this pressure, it was reassuring to learn that the PPP process has endured. For the PPP process to be meaningful and effective, respect for mother's knowledge and insight would need to be paramount—as appeared to be the case with the mother of this study. Much of the literature on mothers' roles in the education of their children with disabilities suggests that although presumed to be equal partners, mothers are often passive partners and primarily the recipients of school based planning and decision making (Lusthaus et al., 1981; Salembier & Furney, 1997). This was not the case with the mothers that this participated in study.

The subtheme “keeping the balance” revealed the mothers efforts to represent their perspectives and input into their children's educational planning through open and ongoing communication, thereby enhancing partnerships between home and school. The

mothers participated in scheduled PPP meetings and maintained personal communication with the school personnel throughout the school year (e.g., classroom teacher, physical education specialist, teacher associate, and resource teacher). Although the utility of the PPP process in inclusive education setting has been questioned (Dudley-Marling, 1985), the mothers recognized that the PPP was the major source of communication between home and school and actively engaged in the process. Consistent with the findings of Garriot et al. (2000) and Salembier et al. (1997), the mothers used the PPP process to explain their children's disability, their children's strengths and weaknesses, and their expectations for educational goals. The mothers also received information regarding their children's performance via the PPP documentation and student progress reports.

The utilization of the PPP was perceived as a useful and necessary tool in their children's education program. Mothers felt that the PPP was a means by which they could see their children's overall education program planning and progression. It was also regarded as a primary tool for expressing their goals and desires of their children to the other PPP members. The mothers presented satisfaction with the PPP process overall, but did indicate that there was variation year to year as teachers changed. The mothers of high school aged children also commented that there was a change in those present at the PPP table and a qualitative difference as increasing student independence was requested and fostered.

Consistent with the findings of Melograno and Loovis (1991), the mothers indicated that the PPP process was not effective in planning for, implementing, or monitoring progress in physical education. These findings support the work of Dudley-

Marling (1985) who twenty years ago suggested the PPP did not assist teachers in day-to-day instruction or qualitatively affect the education of students with disabilities. And yet, the mothers perceived the PPP process to be valuable.

The PPP process appeared to offer a structured mechanism that provided opportunities for mothers to have voice in their children's education. The mothers also indicated, however, that the process is only meaningful if they chose to make it so and take advantage of the opportunity to not only receive information, but bring concerns and issues forward. Living with and raising a child with a disability meant the mothers had unique background information and insights they felt were important to share with school personnel. They also used the PPP form to bring a holistic view of their children forward to balance the perspective of disability as observed (i.e., outsider perspective) (Peters, 1996) which can be deficit based. The mothers in this study brought a strong interventionist perspective to the education of their children. Fortunately, there was a strong partnership between the homes and schools of the participants. This was fostered by open communication and the sharing of responsibilities toward a quality educational experience for their children.

6. SUMMARY AND IMPLICATIONS

Although the mothers of students with disabilities are considered to be advocates for their children within the education setting, their voices have long been neglected in the field of Adapted Physical Education. Thus, the present study focused on listening to mothers' voices, more specifically their perceptions of their children's experiences in inclusive physical education.

The number of values and concerns mothers ascribed to their children's physical education emerged from this study. The mothers felt physical education facilitated social development and provided health benefits. They highlighted barriers to their children's participation including safety, environment, and instruction shortcomings. To counteract perceived limitations to school participation in physical education, the mothers also created opportunities for their children to participate in disability sports outside of school. Mothers played an interventionist role both inside and outside of the school setting. Disability sport within the community was perceived to play an important role in the long term health of their children with disabilities as well providing a source of stimulation for their children's participation in physical education.

Both *segregated* and *inclusive* environments were regarded as necessary to the health and physical well-being of their children with spina bifida. The present study lends empirical support for the need for collaboration between home, school, and the disability community. Disability sports are a place where children with disabilities can learn and build specific sport skills, and school provides an opportunity to perform these skills and have fun with their peers without disabilities. The collaboration between the school and the disability community was seen to be a means by which perceptions of school personnel and peers without disabilities could be positively influenced while also providing information on ways to modify and adapt the physical education program.

Participation in disability sports provided a great deal of information and knowledge to the mothers which they were there able to share with school personnel. The mothers generously gave of their time and expertise to help others understand their children. This active involvement was perceived by the mothers to contribute to the nature of their children's participation in physical education. In turn, the school personnel respected and listened to the parents' voices, thereby making their interventionist role within the school possible. This open communication enhanced teachers' understanding of children, brought disability community programs to the schools (e.g., skiing), and provided disability sensitivity to classrooms.

Although it is very unlikely the mothers of this study were familiar with Peters (1996) model of disablement, they understood the importance of their knowledge and how it could positively influence the educational programming of their children. They recognized the outsider's perspective which objectifies disability and classifies function through a medical model which does not tell the whole story of their children. They

intervened to help inform school personnel and classmates that disability does not mean dis-abled, and did so in part by bringing their children's subjective experiences (or insider's perspective) to the school through the avenue of disability sport.

The active engagement of the mothers may not have been as welcomed without having strong lines of communication established. The mothers indicated that the PPP process, although not specific to physical education, provided an opportunity to be heard.

This study was focused on the mothers' perception of their children's experiences in inclusive physical education. It was not the intention of this study to identify the definition of inclusive physical education perceived by the mothers of children with disabilities, however, future research exploring mothers' and/or fathers' understandings of inclusive physical education is needed. Future studies should consider both mothers and fathers' involvement in their children's physical education programs.

There are still numerous challenges to future researchers in the field of adapted physical education. The mothers in this study chose to be directly or indirectly involved in their children's physical education programs. Not all mothers, however, have the prerequisite knowledge of physical activity, or disability sport to be effective in this regard. Supporting teachers in the teaching of physical education to students with disabilities is very challenging. Tapping into the knowledge and support of parents may have been under recognized previously.

A second issue for future research is the utility of the PPP process in day-to-day classroom activities. Are there other mechanisms better suited to sharing information between home and school that would enhance the teaching and learning experience? Telephone contact, email, internet reporting, and diaries were all mentioned. The

efficacy and efficiency of these forms of communication at the elementary and secondary level has received little attention.

Finally, and perhaps most importantly, is the issue of the preparation of teachers and teacher associate who work with students with disabilities. The mothers consistently expressed the absence of disability knowledge of classroom teachers and teacher associates. How can this student specific, and at times very technical information, be best provided to school personnel and students alike? Many questions arise. How much information, when is it best presented, by whom, within what context, and for what reasons are all questions worthy of future consideration.

It was clear from the study that the education of these students with spina bifida was not the sole responsibility of school. The families took the responsibility for becoming involved and fostering collaboration amongst the school, home, and community. In sharing their experiences, knowledge, and insights it can be argued that all involved benefited.

To further the shared responsibility for the participation of children with spina bifida among teachers of physical education, teaching assistants, and mothers, several areas require future consideration:

- (a) Parents require information about the goals and learning objectives of the physical education program. This could take the form of brochures, workshops, web sites, or direct contact with the teachers of physical education,
- (b) Disability awareness support for teachers is an ongoing need. This information can be made available by contacting parents directly, requesting

disability awareness sessions from the children's physical therapists, teacher friendly information brochures, or web site materials aimed at educators,

- (c) Professional development opportunities for teacher assistants are needed the areas of physical education curriculum, disability sports possibilities, and disability awareness is an ongoing requirement. This may be attainable from on site consultation with educational experts, conference attendance, personal consultation with the children's health care providers, and parents.
- (d) Disability sport and community based recreation and leisure organizations work very closely with parents. There is a need to link these organizations with schools so as to inform teachers and teacher assistants of the potential of children with spina bifida to be involved in sport.
- (e) After school club programs that emphasis disability sports could be established at lead schools. The clubs could include students with disabilities from surrounding schools as well as include children without disabilities from their own schools. Instructional support may be available from disability sport organizations for such programs.
- (f) The forms used in the Personal Program Plan (PPP0 should more closely reflect the curriculum goals and learning objectives of physical education. The current emphasis on fine and gross motor development does not encourage input from teachers of physical education.

Epilogue

As the investigator of this study, I have come to a greater appreciation of the dedication and knowledge that parents possess. I would like to see school personnel recognize the role parents can play in enhancing their children's physical health by maximizing their participation in physical education. I have learned that parents lead very busy and diverse lives. Locating parents that were willing to discuss their children's programs was challenging. Families are very busy and have many priorities which may or may not include active lifestyles.

I came to a significant appreciation for the interview process and the importance of building rapport when asking about the lives of their children who have disabilities. If I were to do this study again, I would include both the mothers and fathers in the discourse. I would seek more families at both the elementary and secondary level so as to have a broader experience base from which to draw. All of the parents of this study had children who were actively involved in disability sport. In a future study I would like to talk to the teaching assistants to determine the nature of their experiences and perceptions of what students with spina bifida require to be successfully involved in physical education. This would provide a more ecological understanding of the experience of physical education

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APPENDIX A: Sample Personal Program Plan

Saskatoon School Division No. 13 Personal Program Plan



SCHOOL YEAR

BACKGROUND INFORMATION

Student Name: _____ Student I.D. #: _____

Male ☐ Female ☐ Date of birth: _____

Parent/Guardian: _____ Telephone Number: _____

Address: _____ Postal Code: _____

_____ Teacher(s): _____

_____ Case Manager _____

_____ (as identified by the team)

Grade/Classroom Placement: _____

Agency Involvement: _____

Program Planning Team: _____

- ☐ classroom teacher(s)

☐ case manager

☐ administrator

☐ parent/guardian

☐ student (if appropriate)

☐ support personnel

• _____

• _____

| Learner Profile (Comment on appropriate categories) | |
|---|-----------|
| Medical Information | Interests |
| Areas of Need | Strengths |

GENERAL PROGRAM SUPPORTS

(Check those supports which are currently in place and specify information)

- ☐ program placement _____
- ☐ resource/itinerant teacher support (name/s) _____
- ☐ teacher associate support: (individual/s) hrs/day _____
- ☐ specialized equipment _____
- ☐ transportation _____
- ☐ other supports (e.g., SLP, counsellor, etc.) _____

SPECIFIC PROGRAM GOALS

(Identify objectives under each appropriate skill area. Indicate n/a if no adaptations are necessary in an area)

1. Social Skills (i.e. attitudes, handling emotions, relationships, etc.)

| Objectives | Strategies/Resources | Progress/Date |
|------------|----------------------|---------------|
| | | |

| 2. Communication (i.e. receptive and expressive, speech or alternative, etc.) | | |
|---|----------------------|---------------|
| Objectives | Strategies/Resources | Progress/Date |
| | | |

| 3. Personal Management (i.e. grooming, dressing, independence in transportation, etc.) | | |
|--|----------------------|---------------|
| Objectives | Strategies/Resources | Progress/Date |
| | | |

| 4. Academics | | |
|--------------|----------------------|---------------|
| Objectives | Strategies/Resources | Progress/Date |
| | | |

| 5. Leisure/Recreation (i.e. free time, lunch, recess, etc.) | | |
|---|----------------------|---------------|
| Objectives | Strategies/Resources | Progress/Date |
| | | |

| 6. Vocational/Work (i.e. work habits such as getting started, working continuously, asking for help, etc.) | | |
|--|----------------------|---------------|
| Objectives | Strategies/Resources | Progress/Date |
| | | |

| 7. Motor Development (i.e. fine or gross) | | |
|---|----------------------|---------------|
| Objectives | Strategies/Resources | Progress/Date |
| | | |

| 8. Other (i.e. sensory development, Braille skills, anger management, technology) | | |
|---|----------------------|---------------|
| Objectives | Strategies/Resources | Progress/Date |
| | | |

| RECOMMENDATIONS/TRANSITION PLANS | |
|----------------------------------|--|
| Date | |

| |
|----------------------------------|
| RECOMMENDATIONS/TRANSITION PLANS |
|----------------------------------|

| | FALL | | SPRING | | JUNE | |
|-----------------|-----------|------|-----------|------|-----------|------|
| | Signature | Date | Signature | Date | Signature | Date |
| Parent/Guardian | | | | | | |
| Teacher(s) | | | | | | |
| | | | | | | |
| | | | | | | |

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APPENDIX B: Ethics Approval

UNIVERSITY OF SASKATCHEWAN
BEHAVIOURAL RESEARCH ETHICS BOARD

<http://www.usask.ca/research/ethics.shtml>

NAME: Donna Goodwin (Irena Jihoun)
College of Kinesiology

BSC#: 03-974

DATE: May 12, 2003

The University Advisory Committee on Ethics in Behavioural Science Research has reviewed the Application for Ethics Approval for your study "Physical Education for Students with Physical Disabilities: Parents' Perspectives" (03-974)

1. Your study has been APPROVED subject to the following minor modifications:

- Please clarify where, in the University of Saskatchewan, the data will be stored.
- Please modify the consent form to state where, and for how long, the data will be stored.

2. Please send one copy of your revisions to the Office of Research Services for our records. Please highlight or underline any changes made when resubmitting.

3. The term of this approval is for 5 years.

4. This letter serves as your certificate of approval, effective as of the time that the requested modifications are received by the Office of Research Services. If you require a letter of unconditional approval, please so indicate on your reply, and one will be issued to you.

5. Any significant changes to your proposed study should be reported to the Chair for Committee consideration in advance of its implementation.

6. This approval is valid for five years on the condition that a status report form is submitted annually to the Chair of the Committee. This certificate will automatically be invalidated if a status report form is not received within one month of the anniversary date. Please refer to the website for further instructions:

<http://www.usask.ca/research/behavrsc.shtml>

I wish you a successful and informative study.

Joanne Franko for
Dr. Valerie Thompson, Chair
University of Saskatchewan
Behavioural Research Ethics Board
C/o Office of Research Services

APPENDIX C: Recruitment Flyer

For further information contact:

Irena An 477 – 5295
irena.an@usask.ca

Donna Goodwin 966 - 1073
donna.goodwin@usask.ca



This project has been approved by
 the University Advisory
 Committee on Ethics in
 Behavioural Science Research at
 the University of Saskatchewan

College of Kinesiology
 University of Saskatchewan
 87 Campus Drive
 Saskatoon, SK S7N 5B2

Physical Education for Students with Physical Disabilities: Parents' Perspectives



A research project of the
 College of Kinesiology
 University of Saskatchewan

Purpose of the Study

The purpose of this study is to understand the role of parents of children with disabilities in their children's physical education programs.



More specifically, this study will describe (1) the value parents place on physical education for their children, (2) the meaning they ascribe to their children's physical education experiences, and (3) the experiences and means of communication parents use to share their ideas about their children's participation in physical education.

Why Your Participation is Important

Through interviews, you will provide a rich and in-depth look at your experiences for your child's physical education program.

Your participation in this study will help others understand the importance of parents' role for their children's participation in physical activity at school and will continue to expand a knowledge based on the issues of inclusion and health and psycho-social promotion.

Who Should Participate?

You are eligible to participate if your child:

- Is between Grade 2 and 10
- Has been involved in an Personal Program Plan (P.P.P) process current to the previous school year,
- Has been active members of the regular school physical education program for at least 2 years,
- Has been involved in a community physical activity or recreation program
- Use a wheelchair as primary form of mobility due to spina bifida

What is Involved?

- ✓ Two one-on-one interviews,
- ✓ Sharing of Children's Photographs
- ✓ Sharing of School Documents
- ✓ Providing feedback on the findings

Research Team

College of Kinesiology,
University of Saskatchewan

- ✓ Irena An, MSc candidate
- ✓ Donna Goodwin, PhD
- ✓ Adam Baxter-Jones, PhD
- ✓ Louise Humbert, PhD



APPENDIX D: Participant Consent Form

UNIVERSITY OF SASKATCHEWAN
College of Kinesiology
Consent Form

You are invited to participate in a study entitled “*Physical education for students with physical disabilities: Parents’ perspectives.*” Please read this form carefully, and feel free to ask questions you might have.

Researchers:

Irena Jihoun An
College of Kinesiology,
University of Saskatchewan
(306) 477 – 5295
irena.an@usask.ca

Dr. Donna Goodwin
College of Kinesiology
University of Saskatchewan
966-1073
donna.goodwin@usask.ca

Purpose and Procedure:

I understand the purpose of this study is to understand the role of parents of children with disabilities in their children’s physical education programs. More specifically, this study will describe a) the value parents place on physical education for their children, b) the meaning they ascribe to their children’s physical education experiences, and c) the experiences and means of communication parents use to share their ideas about their children’s participation in physical education.

This study will require my participation in 2 one-on-one interviews that will last approximately 45 to 60 minutes (total time approximately 2 hours). The interviews will be audio taped and transcribed verbatim (written out). I may be asked to provide feedback on the accuracy of the transcripts and the interpretation of what was said after the information from all the participants has been analyzed.

I understand that I will also be asked to provide documents and photographs that help tell my story. I will explain the significance of the documents during the second interview. I agree to the making of copies of this information so that the researcher can refer back to it at a later time. I am also aware the investigator will be keeping written field notes of her observations and impressions about what was heard during the interview process.

Potential Risks:

I will not be subjected to any physical or psychological risk. I have the right to refuse to answer any question, at which time the discussion will be redirected. Although it is unlikely that the interview questions will induce a negative emotional state, should I feel I would like to discuss issues raised in the interviews further, I will be supported in contacting the SK Spina Bifida Association or the counselling services of the SK Paraplegic Association.

Withdrawal from the study will not affect my or my child’s access to any facilities or services provided by the community or schools. At the time of my withdrawal the data will be deleted from the study and destroyed.

My voice, as a parent of a child with spina bifida will be heard, and although the impact of my story cannot be guaranteed, my participation in this study may contribute to a better understanding of physical education for students with physical disabilities.

All research material will be securely stored in my supervisor's locked office at the University of Saskatchewan for five years, post publication. The audio tapes, transcripts, documents and photographs will be stored separately from the master sheet identifying participant names, pseudonyms, and code numbers.

Confidentiality:

The following steps will be taken to protect anonymity and confidentiality of the verbatim interview transcripts, (a) names or other identifying particulars of the participants will not be discussed or made public outside of the research team (researcher, research assistant, and professional transcriber), (b) pseudonyms will be substituted for all names that appear on the data transcripts and materials for publication, and (c) the audio tapes will be identified by code number only. The data will be presented as general themes that emerge from the transcripts.

The data from this study will be published and presented at conferences; however, my identity will be kept confidential. Although themes from the findings will be supported by direct quotations, I will be given a pseudonym, and all identifying information (e.g., school child attends) will be removed from the report. Only the research team (student, supervisor, and thesis committee members) will review the original materials.

The photographs will be used only to my indicated wishes: (a) as raw data only (viewed only by the research team), (b) for educational purposes (presentation to professional and/or research groups) and publication in scholarly journals only if the photographs are edited to remove those which identify the participants (i.e., only photographs depicting objects or spaces can be released beyond the research team), or (c) the unedited use of the photographs for educational purposes.

Because the participants for this study have been selected from a small group of people, all of whom may be known to each other, it is possible that I may be identifiable to other people on the basis of what I have said. After my interview, and prior to the data being included in the final report, I will be given the opportunity to review the transcript of your interview, and to add, or delete information from the transcripts as I see fit.

Right to Withdraw:

I understand that my involvement in the study is entirely voluntary and participation may be declined or withdrawn at any time without penalty of any sort. Should the researcher feel that my continuation in the project is placing undue pressure on me (e.g. establishing mutual times for interview sessions), she can choose to discontinue my involvement in the study. At the time of withdrawal from the study any data that has been collected will be destroyed.

Questions:

If you have any questions concerning the study, please feel free to ask at any point; you are also free to contact the researchers at the numbers provided above if you have questions at a later time. This study has been approved on ethical grounds by the University of Saskatchewan Behavioural Sciences Research Ethics Board on May 12, 2003. Any questions regarding your rights as a participant may be addressed to that committee through the Office of Research Services (966-2084). I may request a copy of the final report.

Consent to Participate:

I have read and understood the description provided above; I have been provided with an opportunity to ask questions and my questions have been answered satisfactorily. I consent to participate in the study described above, understand that I may withdraw this consent at any time. A copy of this consent form has been given to me for my records.

I also give permission for the photographs I provide to be used under the following circumstances:

- _____ Photographs to be used as raw data only, not to be viewed outside of the research team (student, supervisor, and thesis committee)
- _____ Photographs do not reveal my or my child's identity to be used for educational purposes (professional and research presentations) and research publications.
- _____ Photographs to be used for educational purposes (professional and research presentations) and research publications.

Signature of Participant

Date

Signature of Researcher

Date

APPENDIX E. Participant Information Form

Participant Information Form

Date:

Please provide the following information

| | | | | | |
|---|---|--|--|--------------|--|
| Personal Information | | | | | |
| Name | | | | | |
| Address | | | | Postal Code | |
| Telephone | | | | Email | |
| Date of Birth | <div style="display: flex; justify-content: space-between; padding: 0 10px;"> Parent Child </div> | | | | |
| Age | | | | | |
| Type of Disability | <div style="display: flex; justify-content: space-around; padding: 0 10px;"> Myelomeningocele Meningocele Oculata </div> | | | | |
| Level of lesion | <div style="display: flex; justify-content: space-around; padding: 0 10px;"> Thoracic Lumbar Sacral </div> | | | | |
| Marital Status | <div style="display: flex; justify-content: space-around; padding: 0 10px;"> Single Widows Divorced Married Partner </div> | | | | |
| Education | <div style="display: flex; justify-content: space-around; padding: 0 10px;"> High-school College University Others </div> | | | | |
| Employment | <div style="display: flex; justify-content: space-around; padding: 0 10px;"> <div style="text-align: center;"> Mother Full-Time Part-Time </div> <div style="text-align: center;"> Father Full-time Part-time </div> </div> | | | | |
| Occupation | <div style="display: flex; justify-content: space-around; padding: 0 10px;"> Mother Father </div> | | | | |
| Siblings | <div style="display: flex; justify-content: space-around; padding: 0 10px;"> Brother /Age Sister/Age </div> | | | | |
| Community Program Information | | | | | |
| Kinds of Activity (e.g. swimming, dance, etc.) / Duration | | | | | |
| Type of Program | only children with disability | | | all children | |

| | | |
|--|-------|---------------------|
| School Information | | |
| Which School/Grade | | |
| How long has your child attended at a present school? | | |
| Have you ever changed your child's school? if so, why? | | |
| Who is teaching the physical education program? | | |
| a. Classroom Teacher b. Physical Education Specialist | | |
| Is there a teaching assistant (TA)? | | Yes/No |
| a. Full time b. Part-Time | | |
| Does a TA attend Physical Education with Children? | | Yes/No |
| Is Gym fully accessible (e.g., no stairs)? | | Yes/No |
| Personal Program Plan (P.P.P) | | |
| P.P.P Meeting (How many per year) | | |
| How many are you attended? | | |
| Who attends the meeting? | | |
| Child's Attendance | | Yes/No |
| Parents' Attendance | Alone | With Spouse/Partner |

APPENDIX F: Interview Guide

Interview Guide

- 1) Tell me about your child's physical education program
Probes:
 - a) How important it is for your child to participate in the physical education program?
 - b) What are your child's preferred/non preferred activities?
 - c) When is it appropriate for your child to participate/not participate?
 - d) What role does physical education play in your child's overall school experiences?
- 2) What would you like to see your child doing in physical education?
Probes:
 - a) What would you not like to see your child doing in physical education?
 - b) What role does physical activity play in your family's life?
- 3) How would you describe your child's participation in physical education?
Probes:
 - a) What role does the instructional assistance that accompanies your child to physical education play?
 - b) How important is that person to your child's participation?
- 4) What do you anticipate for your child's future participation in physical education?
Probes:
 - a) Later elementary?
 - b) High school?
- 5) What opportunities are there to discuss your child's physical education program?
Probes:
 - a) What options exist beyond the report card reporting periods?
 - b) How would you describe your role in these settings?
 - c) What role does your child play?
 - d) How would you rate your satisfaction with these opportunities? Explain
 - e) Would you change these opportunities? If so how?

APPENDIX G: Member Check Forms



Irena Jihoun An
(306) 251-1469
irena.an@usask.ca
246 Davies Road
Saskatoon SK S7K 7N1

May 20, 2005

Dear _____ :

I am happy to say the data analysis of the research study titled *Physical Education for Students with Physical Disabilities: Parents' Perspectives* has been completed. I would like your feedback on the accuracy of my summary of your stories and insights. Please look over the enclosed summary of results. If there is anything that you wish to change or include, you can either complete the enclosed form and send it back to me in the enclosed envelop or email me your feedback (irena.an@usask.ca).

Once again thank you for participating in my research and please do not hesitate to contact me if you have any questions about the study(251-1469) Your involvement in the study has made a significant contribution to my understanding of the Physical Education for Students with Physical Disabilities. Thank you for your ongoing commitment.

Sincerely,

Irena Jihoun An

Physical Education For Students with Physical Disabilities
Parents' Perspectives
Summary of Thematic Analysis

Three themes emerged from the thematic analysis of parents' perceptions of the inclusive physical education for children with physical disabilities: (a) a good thing but..., (b) connection to disability sports, and (c) beyond the curriculum. The themes are supported by subthemes that further explicate the experiences of the parents.

1. A Good Thing But...

The first theme expressed the parents' feelings that physical education was very beneficial to their children in the aspect of health and social skill improvement. Although the mothers recognized the benefits of their children's involvement in physical education, they also expressed concerns of barriers to participation.

A. Supports Development:

The mothers recognized the important role physical education played in social development, including friendship, the sense of belonging, enjoyment, and self-confidence. The health benefits of physical activity as an intervention against obesity brought about by sedentary lifestyles were expressed.

B. Participation Barriers:

The barriers described by the mothers were related to safety (specific learning activities, facilities), the environment (equipment, wheelchair accessibility), and instruction (curricular adaptation, knowledge of disability, and availability of support)

2. Connection to Disability Sports

The mothers indicated how their children's school physical education experiences helped prepare them for more specialized disability sports experiences in the community. In turn, the community disability sport experiences resulted in more active participation in selected components of the school physical education program. The link between the school and the community was a mutually beneficial one.

A. Enhanced School Participation

The mothers believed the experiences of disability sports (e.g., sit-skiing, swimming, wheelchair sports) would give their children a better understanding of physical activity and facilitate their participation in school physical education.

B. Developing Disability Sports Skills

Since the mothers felt that participation challenges limited opportunities to learn some physical activity skills in physical education. They wanted their children to also benefit from disability sport opportunities through community programs.

3. Beyond the Curriculum

The last theme reflects the role the mothers played in helping others understand their children. They worked to demystify the wheelchair and explain to teachers, instructional assistants and classmates what spina bifida was. They also highlighted their children's abilities and how similar their needs were to that of other students.

A. Bringing a Different Frame of Reference

The mothers highlighted their participation in two forms of disability awareness in the school. The first was the information about spina bifida and its impact of movement and mobility. The second was disability sports awareness that included information and practical sessions on sports participation using wheelchairs. These sessions were in some instances lead by the parents or the parents were instrumental in bringing others into the school.

B. Keeping the Balance

Communication with the school was made by the PPP process and individual contact (i.e., teachers, teacher associate, or resource teacher). Parents described the importance of parents' role in their children's program as it gave teachers a better understanding about their children.

Physical Education For Students with Physical Disabilities
Parents' Perspectives
Summary of Thematic Analysis

Please complete and return using the provided envelop.

Name: _____

Address: _____

_____ Yes, I can see my experiences in the themes as they are described.

_____ No, I cannot see my experiences in the themes as they are described.

What, if anything, would you like to change/add/delete?

1. A Good Thing But...

2. Connection to Disability Sports

3. Beyond the Curriculum

Signature/Date

Thank You